MAMMOGRAPHY BEHAVIORS IN MULTIPLE SCLEROSIS

Mammography Screening Behaviors in Relation to the Expanded Health Belief Model in a Sample of Homebound Women with Multiple Sclerosis

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The purpose of this study was to determine the relationship between variables of the Expanded Health Belief Model (EHBM) including: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors; and adherence to mammography screening in homebound women with Multiple Sclerosis (MS). The sample was derived from the National Multiple Sclerosis Society from a group of women in Allegheny County who received an intervention program titled "*Home-based Health Maintenance Program for Women with MS.*" The program provided home visits by a nurse midwife who educated women with MS and their partners about breast cancer, as well as provided an appointment for a mammogram.

The correlational, descriptive design used a telephone interview for data collection. Due to the lack of subject accrual, the study was subsequently divided into two phases. Phase One was an analysis of 149 women who were approached to complete the intervention program through de-identified data sent by the National Multiple Sclerosis Society (NMSS). Phase Two was the dissertation study of homebound women consisting of a telephone interview measuring EHBM variables with the instruments chosen. The battery included the Breast Cancer Knowledge Test, the Benefits and Barriers Mammography Scale, Short Form-36, Beck

Depression Inventory-II edition, Mini-Mental State Examination, the Mammography Screening Self-Efficacy Scale, and physician recommendation for mammogram.

The de-identified data in Phase One revealed that out of 149 women approached, 108 women received the intervention program. None of these women had a mammogram in the last year. Only 7 (6%) women had a mammogram, none were diagnosed with breast cancer, and no correlation was found between smoking and mammography screening adherence.

In Phase Two, out of all the EHBM variables analyzed, the data suggests bivariate association between perceived susceptibility, severity, benefits, and self-efficacy with mammography screening adherence. Due to the small sample size and sparse cell sizes, binary logistic regression was not able to investigate the joint associations of EHBM predictors.

Mammography is the primary method used for breast cancer screening, yet in the sample of women with MS, adherence remains well below recommended levels. Women who did not adhere tended not to participate in the health care system, perceived themselves less susceptible to breast cancer, and valued mammography less. It was also evident that physician referral was not important in this study. The study had several limitations including a small sample size, the minimal data obtained from the NMSS, and the short study duration. Future recommendations include a longitudinal study design, incorporation of family caregivers, and an increase in recruitment strategies.

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1.0 STATEMENT OF THE PROBLEM

Multiple Sclerosis (MS) is a disease characterized by recurrent or chronically progressive neurological dysfunction caused by inflammatory changes in the white matter of the central nervous system (CNS). The inflammatory changes result in widespread demyelinated and sclerotic lesions or plaques (Appendix A). Affected individuals have these changes in the brain, optic nerve, and spinal cord (McDonald, 2001). Relapsing-remitting MS is the most commonly occurring type and is found in 80% of patients (Noseworthy, Lucchinetti, Rodrigues, & Weinshenker, 2000). The symptoms and signs typically evolve over a period of several days, stabilize, and then often improve within weeks with or without corticosteroids. The disability manifests itself with sensory disturbances, trunk and limb paresthesias evoked by neck flexion (Lhermitte's sign), limb weakness, and gait ataxia (Appendix B). Individual bouts of inflammatory demyelination may be accompanied by clinical symptoms (relapse) followed, in most cases, by some degree of recovery. The signs of central nervous system dysfunction may even progress between relapses causing secondary progressive MS. Eventually, cognitive impairment, depression, emotional lability, dysphagia, vertigo, progressive quadriparesis, ataxic tremors, fatigue, pain, and spasticity develop (Noseworthy et al., 2000).

The overall prevalence of MS is about 1 in 700 or 0.14% of the population in the United States (U.S.). A reported 250,000 to 500,000 cases have been reported in the U.S. (NMSS, 2004). MS is the most common, non-traumatic, disabling neurological disease that occurs in

young adults, primarily in women. The disease has its peak onset at approximately 30 years of age, with the first symptoms usually occurring between the ages of 15 and 50 years. Women are affected at rates two to three times greater than men. In all studies, the highest age- and gender-specific rates occur in women between the ages of 20 and 40 years. Consequently, disability occurs at a time when women are most active in their work, social, and family responsibilities.

The Allegheny District Chapter (ADC) of the National Multiple Sclerosis Society (NMSS) identified nearly 2,000 people with MS living in Allegheny County in 1999. Overall, the Allegheny District itself has identified 4,900 people with MS in the 23 counties they cover. Of those, 1,460 were women. Further, 18% of all persons with MS have significant disability requiring them to be homebound due to neurologic impairments. Therefore, approximately 260 women with MS in Allegheny County are projected as homebound due to significant impairment (NMSS, 1999).

The physical disabilities associated with MS cause women to be at higher risk for delayed diagnosis of other chronic diseases. Modalities, such as interferon beta-1a and b, immune-mediating agents that may be used for treatment, and glatiramer acetate, reduce the proliferation of T cells, possibly inducing the formation of neutralizing antibodies and increasing the risk of developing other diseases such as cancer (Noseworthy et al., 2000). Thus, people with MS may be at higher risk for cancer as compared to the general population. Interventions aimed at improving adherence to screening recommendations for some chronic diseases may lead to early detection, and an increased rate of survival in persons with MS.

An estimated 211,240 women are expected to be diagnosed with breast cancer in 2005 (American Cancer Society, 2005). Recommended screening methods for breast cancer include mammography, clinical breast exam (CBE), and self-breast exam (SBE) (Appendix C). Annual

mammography screening is recommended for women 40 years of age and older (American Cancer Society, 1998; U.S. Preventive Task Force, 2002). Barriers to screening in women with MS, such as physical mobility and cost, decrease adherence to these screening recommendations (U.S. Department of Health and Human Services, 2000).

Underutilization of mammography screening is associated with the disease of MS, as evidenced by markedly disparate annual mammography screening rates observed among women with MS who are 40 years of age and older compared to their healthy counterparts of similar age. According to the NMSS (1999), 1.5% of women with MS receive mammograms. In contrast, mammography screening rates in the general population are 80% (U.S. Department of Health and Human Services, 2000). Few, if any, interventions are targeted to increase adherence to mammography screening recommendations in women with MS.

The probability that women will participate in early detection behaviors can be predicted from individual variables, such as barriers/benefits, and from demographic/sociopsychological factors, such as age and education (Rutledge, Barsevick, Knobf, & Bookbinder, 2001). The Expanded Health Belief Model (EHBM) has been used to explain change and maintenance of health behavior and as a guiding framework for health behavior interventions (Strecher & Rosenstock, 1997). While components of the Expanded Health Belief Model (including perceived barriers and benefits) are well established for healthy women, no studies have examined the extent to which MS-related barriers contribute to underutilization of mammography by women with MS.

The NMSS has established a program in Allegheny County titled “Home-based Health Maintenance Program for Women with MS.” The program provides underserved women with MS access to early detection procedures related to breast care. The program provides home

visits by a nurse midwife who will educate women with MS and their partners in breast exam techniques and risk factors for breast cancer. The program provides appointments for mammograms.

The purpose of this study is to determine the relationship between variables of the EHBM (perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors) and adherence to mammography screening in homebound women with MS residing in Allegheny County who complete the NMSS intervention.

1.1 RESEARCH QUESTION

1.1.1 The research question of this study is:

Is there an association between perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors of breast cancer and post-intervention mammography screening adherence in homebound women with MS?

The hypotheses for this study are:

1. There is a positive correlation between perceived susceptibility and post-intervention mammography screening adherence rates in homebound women with MS.
2. There is a positive correlation between perceived severity and post-intervention mammography screening adherence rates in homebound women with MS.

3. There is a positive correlation between perceived benefits and post-intervention mammography screening adherence rates in homebound women with MS.
4. There is a negative correlation between perceived barriers and post-intervention mammography screening adherence rates in homebound women with MS.
5. There is a positive correlation between cues to action and post-intervention mammography screening adherence rates in homebound women with MS.
6. There is a positive correlation between self-efficacy and post-intervention mammography screening adherence rates in homebound women with MS.
7. There is a correlation between modifying variables: a positive correlation with educational attainment and a negative correlation with increasing age and non-white races, and post-intervention mammography screening adherence rates in homebound women with MS.
8. There will be an interaction between at least one or at most all variables including perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors and post-intervention mammography screening adherence rates in homebound women with MS. A positive interaction will occur between perceived susceptibility, perceived severity, and modifying factors for adherence. In addition, there will be a negative interaction between perceived barriers and cues to action for adherence.

1.2 DEFINITION OF TERMS

I. PERCEIVED SUSCEPTIBILITY: beliefs about a woman's risk for developing a breast cancer as measured by the Breast Cancer Screening Knowledge Test.

II. PERCEIVED SEVERITY: beliefs concerning the seriousness and curability of breast cancer as measured by the Breast Cancer Screening Knowledge Test.

III. PERCEIVED BENEFITS: beliefs regarding the effectiveness of mammography screening in reducing the threat of breast cancer as measured by the Benefits subscale of the Benefits and Barriers Mammography Screening Test.

IV. PERCEIVED BARRIERS: potentially negative aspects of the mammography screening including cost of healthcare (as measured by health insurance coverage), inconvenience (as measured by self-report of specific difficulties of facility access), physical impairment (as measured by the SF-36 subscale of physical function), depressive symptomatology (as measured by the Beck Depression Inventory, 2nd edition), and mental status changes (as measured by the Mini-Mental State Examination for screening purposes).

V. CUES TO ACTION: triggers of bodily and environmental events that instigate the action to have a mammogram as measured by self-report of physician recommendation within one year.

VI. SELF-EFFICACY: the appraisal of one's ability to successfully obtain mammography under varying conditions as measured by the Mammography Screening Self-Efficacy Scale.

VII. MODIFYING FACTORS: other diverse demographic variables including education level, age, and race that interact with other factors and may affect a woman's perception and indirectly her health-related behavior of obtaining a mammogram.

VIII. POST-INTERVENTION MAMMOGRAPHY SCREENING ADHERENCE: whether or not a woman chooses to keep her appointment for a mammogram within 2 months of the scheduled appointment as measured by the appointment keeping variable in the NMSS data set.

IX. HOMEBOUND WOMEN with MS: women with MS that restricts their ability to leave their home except with the assistance of another individual or the aid of a supportive device (such as crutches, a cane, a wheelchair, or a walker), or that makes leaving her home medically contraindicated. If the woman does leave the home, it requires a considerable and taxing effort, and the absences from the home are infrequent or of relatively short duration, or are attributable to the need to receive medical treatment. This determination is made over a period of time.

X. MULTIPLE SCLEROSIS: a diagnosis made by a physician in accordance with the guidelines established by the NMSS (see Appendix A).

2.0 INTRODUCTION

The medical costs associated with all disability in the U.S. are more than $300 billion annually, or 4% of the gross national product (Institute of Medicine, 1997). This total cost includes $160 billion in medical care expenditures (1994 dollars) and lost productivity of almost $155 billion. The health promotion and disease prevention needs of people with disabilities are not nullified because these individuals are born with an impairing condition or have experienced a disease or injury that has long-term consequences (U.S. Department of Health and Human Services, 1991). Populations with disabilities due to chronic conditions have increased health concerns and susceptibility to secondary conditions (U.S. Department of Health and Human Services, 2000). For those with a chronic illness, suffering may result not only from physical limitations, but the psychosocial characteristics of being physically disabled.

Populations who have activity limitations report having more days of pain, depression, anxiety, and fewer days of vitality during the previous month than people without activity limitations (Center for Disease Control and Prevention, 1998). The emotional distress associated with disabilities does not appear to arise from physical limitations, but rather environmental barriers that reduce the individual's ability to participate in life activities. Due to the disability associated with MS, it is particularly important to target activities and services that address all aspects of health, including promoting health, preventing secondary conditions and environmental barriers, and providing access to medical care.

As a potentially underserved group, those with disabilities may experience disadvantages in health and well-being compared with the general population. Disparities between those with disabilities and the general population have been noted. These disparities include less frequent mammograms for women over age 55 years who are disabled (55%) compared to those who are not disabled (67%), (U.S. Department of Health and Human Services, 2000).

This chapter will include a description of the conceptual model that will be used to guide the study, EHBM. Following this, a literature review will include a discussion of variables that contribute to the research purpose, in particular, cancer screening in the general population, MS and cancer, breast cancer screening and MS, and specific MS disease-related factors that may present as barriers to mammography screening adherence.

2.1 CONCEPTUAL MODEL

The EHBM has been one of the most widely used models for explaining change and maintenance of health behavior, as well as for development of health behavior interventions (Strecher & Rosenstock, 1997). The HBM was developed in the 1950s by a group of social psychologists in the U.S. Public Health Service in an effort to explain the widespread failure of people to participate in programs to prevent or detect disease (Hochbaum, 1958; Rosenstock, 1960, 1966). The model was later extended to include application to people's responses to symptoms (Kirscht, 1974), and to their behavior in response to illness and its management (Becker, 1974). The HBM model originated as a value expectancy theory (Strecher & Rosenstock, 1997). The concepts were gradually reformulated in the context of health-related behavior to include the assumptions that one has the desire to avoid illness or to get well (value)

and a belief that a specific health action available to that person would prevent illness (expectancy).

Over the four decades of the development of this model, investigations have expanded and clarified the model and have extended its application to preventive actions and illness and sick-role behaviors (Becker & Maimam, 1980; Janz & Becker, 1984; Kirscht, 1974; Rosenstock, 1974). In general, it now is believed that individuals will take action to ward off, screen for, or control an ill-health condition if they regard themselves as susceptible to the condition, if they believe:

1. It to have potentially serious consequences,
2. That a course of action available to them would be beneficial in reducing either their susceptibility or the severity of the condition,
3. That the anticipated barriers to or costs of taking the action are outweighed by its benefits,
4. There are cues to action present. In addition, self-efficacy was added to the model to increase explanatory power (Rosenstock, Strecher, & Becker, 1988).

Self-efficacy is the "conviction that one can successfully execute the behavior required to produce the outcome" (Bandura, 1977). If self-efficacy is lacking, then another barrier is added to taking a recommended health action. The key variables of the EHBM now include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action (see Table 1). A general variable of modifying factors, includes demographic, sociopsychological, and structural variables.

Table 1: Key Concepts and Definitions of the Health Belief Model (Strecher & Rosenstock, 1997)

CONCEPT	DEFINITION	APPLICATION
Perceived susceptibility	One's opinion of chances of getting a condition	Define populations at risk
Perceived severity	One's opinion of how **s**erious a condition is	Specify consequences of risk
Perceived benefits	One's opinion of the efficacy of the advised action	Define action to take
Perceived barriers	One's opinion of the tangible and psychological costs of the advised action	Identify and reduces with help
Cues to action	Strategies to activate one's "readiness"	Promote awareness
Self-efficacy	One's confidence in one's ability to take action	Demonstrate desired behavior
Modifying factors	One's demographic, sociopsychological, and structural variables	Education, age, and race

The predictors used in this study of the EHBM will be applied to a sample of woman with MS regarding decision making processes in participating in mammography screening. The seven concepts include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors of breast cancer are the independent variables. The dependent variable is therefore adherence to mammography screening, detecting the occurrence of breast cancer. The cue to action is the appointment for the mammogram made by the nurse midwife (Appendix D).

2.2 LITERATURE REVIEW

2.2.1 Cancer Screening in the General Population

Breast cancer is the leading cause of cancer mortality in woman age 15-54 years. As the number of women from the so-called “baby boom” generation age, breast cancer cases and deaths are expected to increase substantially (U.S. Department of Health and Human Services, 2000). The routine use of mammography screening in women older than 50 years of age has been shown to lower the likelihood of dying from breast cancer by 20-30%.

2.2.2 Susceptibility

Factors positively associated with the regular use of screening mammography include family history of breast cancer and belief of greater personal risk. Lauver, Nabholz, Scott, & Tak (1997)

found that belief in one's risk of breast cancer and family history were most related to adherence or the intention to obtain a mammogram in a sample of Midwestern women (*N*=178).

Intentions to have a mammogram have also been found to be associated with perceived susceptibility in breast cancer (Savage & Clark, 1996). Perception of the risk conferred by family and medical history has been shown to be a strong predictor of breast cancer screening behavior in women (*N*=1,083) 50 years of age and older (Miller & Champion, 1996). Similarly, Rutledge et al. (2001) measured risk index and predisposing variables of susceptibility and found that actual breast cancer risk accounted for a moderate amount of the variability in mammography screening behavior.

On the other hand, Lauver, Kane, Bodden, McNeel, & Smith (1999) found that women who had negative moods and no history of asymptomatic breast problems (*F*=2.58, *p*=.04) were more likely to have mammograms. Breast cancer risk factors were not predictive of whether women adhered to mammogram appointment (*N*=171, age 50-69), even if they did not have a mammography performed in the preceeding 2 years (Beaulieu, Beland, Roy, Falardeau, & Herbert, 1996).

2.2.3 Severity

There is little documentation that perceived severity alone predicts mammography behavior. Swedish women who worried most about developing breast cancer were most likely to obtain a mammogram (*OR*=0.9, 95% *CI*=0.02-0.31). Holm, Frank, and Cutin, (1999) found that among women who participated in mammography screening, perceived seriousness or severity were not significant predictors of mammography behavior.

Champion (1992) has completed numerous works with the Health Belief Model and mammography screening behavior. Along with the other model variables, she found that adherence with mammography screening was influenced by perceived seriousness (or severity) of breast cancer. In addition, data were collected during home interviews with 405 women over age 40 (Champion, 1994). Women compliant with mammography guidelines had significantly higher scores on seriousness in relation to different stages of mammography adoption (precontemplation, contemplation, and action/maintenance).

2.2.4 Benefits

Han, Williams, and Harrison (2000) used Champion's instrument to evaluate practices in breast cancer screening in relationship to the incidence of breast cancer in a sample of Korean American women, a population in which the incidence of the disease has been increasing. Benefits were determined by breast cancer knowledge and attitudes and were measured using the Breast Cancer Knowledge Instrument. Evaluation was completed through a survey that was mailed to and completed by a total of 107 women. It was found that women who never had a mammogram reported significantly higher perceived barriers [$t(102)]=3.794$, $p<0.01)$] as compared to those who had a mammogram and reported more benefits.

Attitudes, beliefs, and knowledge were investigated as predictors of attendance in a Swedish population-based mammography screening program (Lagerlund, Hedin, Sparen, Turfjell, & Lambe, 2000). The predictors of program compliance in this group were women who had knowledge of the perceived benefits from screening (*OR*=0.35, 95% *CI*=0.08-0.75).

Additionally, the HBM has been used to examine women's mammography behavior (Holm, Frank, & Curtin, 1999). Champion's health belief scales were used to measure HBM

variables for rating perceived benefits. The sample consisted of 25 African American and 72 Caucasian women age 35 to 84 years. It was found that women who participated in mammography screening were more likely to perceive greater benefit from the screening (Spearman's correlation=.25, $p<.05$). Perceived benefits were significantly correlated with shorter duration of time since last mammogram.

2.2.5 Barriers

Kash, Holland, Halper, and Miller (1992) investigated the beliefs of women at high risk for breast cancer about their breast cancer risk and the impact of this information on their surveillance behaviors and psychological distress as measured by the Brief Symptom Inventory. Out of 217 women, 94% had regularly scheduled mammograms. Women reporting more barriers to screening (emotional distress, transportation problems, and physical discomfort from the procedure) had fewer social supports, and those with low social desirability had more distress secondary to anxiety ($r=.75$). The interpretation is that these women knew to get the mammography screening done, and if they did not, they experienced anxiety from nonadherence.

Additionally, Han et al. (2000) found that woman who never had a mammogram reported significantly more perceived barriers $\{t(102)\}=3.794$, $p<0.01$) as compared to those who have had a mammogram. Holm et al. (1999) also found that women who participated in mammography screening perceived fewer barriers (Spearman's correlation=.204, $p<.05$). On the other hand, Rutledge et al. (2001) found that barriers did not account for variability in mammography screening behavior.

2.2.6 Cues to Action

Investigations of cancer mammography screening adherence behaviors and associated predictors have been conducted in the general population. Some of these studies have been guided by the HBM. Absence of screening mammography during four calendar years (1989 to 1992) before the diagnosis of breast cancer was more frequent among women with late stage breast cancer than their healthy counterparts (42.1% versus 57.7%, age adjusted *OR*=1.9, 95% *CI*=1.3-3.3), (Wu, Weissfeld, Weinberg, & Kuller, 1999). Beaulieu et al. (1996) performed a secondary analysis of data from a nonrandomized study to determine factors related to adherence with screening mammography in women (*N*=171) age 50-69 years with no mammography performed in the preceeding 2 years and no history of breast cancer. The women were given a written prescription while in a clinic. This recommendation was followed by a telephone questionnaire based on the HBM. Of the 171 eligible women, 113 (66.1%) underwent the prescribed mammography within 2 months of the clinic visit. The strongest predictor of adherence to mammography was the number of previous mammograms. Women who had undergone mammography previously were significantly more compliant that those who had not a previous mammogram (*OR*=0.21, 95% *CI*=0.0007-0.60, *p*=.0004).

Physician communication is a factor that has been investigated in relation to mammogram screening in women. MacDowell, Nitz-Weiss, and Short (2000) found two significant predictors of breast cancer screening in women ages 50 to 79 years: a woman's belief that she should get a mammogram one or more times a year and her willingness to get a mammogram if the physician recommends it.

Han et al. (2000) found that women who had encouragement from family members were four times more likely to have had a mammogram, women who received encouragement from

physicians six times more likely. Nonattendance to mammography screening program was related to lack of advice from the woman's health care professional.

2.2.7 Self-Efficacy

Matthews (1997) developed the Mammography Screening Self-Efficacy Scale (MSSS) to measure the strength and generality of women's efficacy expectations in relation to mammography. Preliminary work on the scale was completed in women age 40 and older in a sample obtained from a local university. Of the women age 50 and older who completed the scale (N=29), twenty-two (92%) had ever had a mammogram. Total scores ranged from 1 to 350 (M=272; SD=99) for the first administration of the instrument. Two weeks later, women who had never had a mammogram or were overdue for one scored significantly lower (M=199; SD=123; p<.05) at Time 1 than did women who had a mammogram in the last year (M=296; SD=79).

The MSSS was further evaluated in a subsequent pilot intervention study of 27 female family caregivers age 50 and older designed to evaluate the responsiveness of non-adherent caregiving women with a nurse delivered communication to improve mammography screening adherence. There was an increase in adherence to mammography screening after a home visit was completed by the nurse with the caregiving women (p>.05).

Holm et al. (1999) found that women who participated in mammography screening had greater health motivation (Spearman's correlation=.386, p<.01). On the other hand, Rutledge et al. (2001) analyzed general health motivation and found that the variable did not account for variability in mammography screening adherence.

2.2.8 Modifying Factors

Diverse demographic and sociopsychological variables may effect an individual's perception and thus indirectly influence health-related behavior. Miller and Champion (1996) have researched mammography behavior related to these modifying factors. Relationships were examined between selected demographics (age, race, income) and adherence to mammography guidelines. A logistic regression analysis was not significant for any of these demographic factors. However, previous work with the Health Belief Model by Champion has shown that age, socioeconomic status, and race are significantly related to actual adherence to mammography (Champion, 1992).

Rutledge et al. (2001) measured age (mean age of 60 years), education, residence, knowledge of breast cancer and detection method and found that age, physician encouragement, and breast cancer risk accounted for (50%) of the variability in mammography screening adherence in women.

Lee and Vogel (1995) supported that regular care from gynecologist and higher education level were associated with regular use of screening mammography. Age was most related to adherence or intention to obtain mammogram in a study completed by Lauver et al. (1997). Lagerlund et al. (2000) found that nonattendance to mammography screening program was found to be related to less knowledge about mammography and breast cancer. Lauver et al. (1999) found that those with private insurance (F=2.76, p=.04) were more likely to have mammograms.

Conversely, Qureshi, Thacker, Litaker, and Kippes (2000) found that modifying factors of ethnicity, alcohol use, marital status, and educational level were not significantly associated with mammography screening adherence. Additionally, Beaulieu et al. (1996) found that

socioeconomic (income), perceived health status, and health utilization indices were not predictive of whether women adhered to the mammogram appointment.

To summarize, the evidence is clear that perceived susceptibility, perceived severity, perceived benefits, cues to action, self-efficacy, and specific modifying factors can increase adherence to recommended screening. On the other hand, barriers including cost, inconvenience, and lack of knowledge decrease adherence to mammography screening.

2.3 MULTIPLE SCLEROSIS AND CANCER

MS and cancer are both chronic diseases. While the causes of both diseases remain elusive, some risk factors for MS are also risk factors for cancer. Smoking, a risk factor for cancer, has also been associated with increased risk of developing MS (Willett, 1996), according to analysis of data from the Nurses' Health Study I and II. Conversely, this study did not support dietary fat intake as a risk for MS as with cancer. Studies have also supported a strong association between dietary animal intake and MS (Willett, 1996). In addition, there is evidence to suggest that MS itself and treatment of the disease possibly render the person more susceptible to a secondary diagnosis of cancer (Confavreux et al., 1996).

MS is a chronic inflammatory disease principally characterized by a progressive demyelineation of the lipoprotein sheath (Swain, 1996), resulting in clinical symptoms, which include vision changes, fatigue, and gait ataxia. The theories of the specific etiology of MS include viral and genetic, environmental, and immunologic factors. The main goal of MS treatment is to improve the patient's quality of life by delaying disease progression, managing symptoms, and treating acute exacerbations. Immunosuppressive agents are now being used to

slow disease progression. Beta-interferon is used to stimulate the immune system by enhancing natural killer cell activity, activating macrophages, and inhibiting virus replication (Francis, 1993).

Confavreux et al. (1996) assessed the long-term risk of neoplasia in a case-control study of MS patients treated with azathioprine, an immunosuppressive antimetabolite. The cases were MS patients who also had a diagnosis of cancer, and the controls were patients with MS who were cancer free. Fourteen cases (61%) and 34 controls (49%) had been treated with azathioprine for at least 1 month after being diagnosed with MS (adjusted *OR*=1.7, 95% *CI*=0.6-4.6). Odds ratios for cancer in MS patients were 1.3 (95% *CI*=0.4-4.0) when treated less than 5 years with azathioprine, 2.0 (95% *CI*=0.4-9.1) when treated 5 to 10 years with azathiorine, and 4.4 (95% *CI*=0.9-20.9) when treated for more than 10 years with azathioprine. The results are suggestive of a dose-response relationship with no significant increased risk of cancer during the first years of treatment and a possible increased risk after about 10 years of continuous therapy with azathioprine.

The reduction of the proliferation of T cells can induce the formation of neutralizing antibodies and increase the risk of cancer. Thus, during the extended disease course of MS, there are ample opportunities for the patient to develop cancer as a potential long-term complication of immunosuppressive drug treatment (Midgard et al., 1996). Investigators retrospectively analyzed data from the Norwegian Cancer Registry since 1952. A total of 1,271 individuals were identified with MS, 530 men and 741 women. In this sample of persons with MS, 73 cases of breast cancer were identified [standardized incidence ratios (*SIR*)=0.86, 95% *CI*=0.68-1.09]. In addition, breast cancer was observed in significantly more women with MS as compared to the general population (*SIR*=1.70, 95%*CI*=1.05-2.60).

The underlying cause of death in Danish patients with MS has also been studied retrospectively (Koch-Henriksen, Bronnum-Hansen & Stenager, 1998). In this case, data were obtained from the Danish Multiple Sclerosis Registry. Data were collected between the years 1949 and 1993, and diagnosis was confirmed through specific diagnostic codes. A total of 6,068 people with MS died within this period of time. MS was the direct cause of death in 55.4% of the sample. Cancer was the cause of death in 8.6% of the sample of Danish patients with MS [standardized mortality ratio (*SMR*)=0.79, 95% *CI*= 0.70-0.90]. When compared to other causes, patients with MS in the Danish sample had a significantly reduced risk of dying from cancer. The diminished risk of dying from cancer may be a result of incomplete diagnosis of cancers in disabled patients with MS in this sample.

To summarize, some risk factors for cancer are also risk factors for MS. Additionally, treatment for MS may render the person more susceptible to some forms of cancer, in particular breast cancer. Increased incidence of breast cancer has also been reported to be a comorbidity with MS in Denmark and Norway (Koch-Henriksen et al., 1998).

2.3.1 Breast Cancer Screening and Multiple Sclerosis

Breast and cervical cancer screening rates among those with physical disabilities have been reported (U.S. Department of Health and Human Services, 2000). The National Study of Women with Physical Disabilities analyzed data from 450 women (age 18 to 65 years) with a variety of physical disabilities (Nosek & Howland, 1997). Ten percent of these women had a diagnosis of MS. In addition, 393 friends of the study subjects were used for comparison. Outcomes measured included frequency of mammograms. No significant difference was found in mammography behavior within the preceding two years between women with and without

disabilities regardless of severity of functional limitation. The factor of perceived control over functional limitations was found to be a significant factor for participation in mammography screening. The severity of disability, race, household income, and age were not significant predictors of screening behaviors. The authors concluded that women with disabilities are at higher risk for delayed diagnosis of breast and cervical cancer primarily for reasons of environmental, attitudinal, and informational barriers as compared to a group of women without disabilities. Kiefe, Funkhouser, Fouad, and May (1998) conducted a structured medical record review of a defined cohort of patients with chronic diseases, including cancer. They found that mammography screening rates decreased as comorbidity increased ($p<.05$ for linear trend).

Weiner (1998) reported that there are 25 million women with disabilities in the U.S. Barriers include lack of knowledge, inability to identify who is their primary care provider, and physical inaccessibility, which delay diagnosis and treatment of cancers and osteoporosis. Shabas and Weinreb (2000) surveyed preventive practices of 220 women with MS. Their objectives were to evaluate the adequacy of the detection and prevention of osteoporosis as measured by frequency of x-ray scans, cervical cancer as measured by frequency of Pap smears, and breast cancer screening as measured by frequency of mammograms. Their survey revealed that 50% of the women did not get regular medical preventive checkups, and in women over 40 years of age, 52% did not have yearly mammograms.

The benefits of preventive health care and cancer prevention screening have not been stressed in women with MS. Clearly, health maintenance of women with disabilities such as MS, needs to be greatly emphasized by health care professionals.

2.3.2 Multiple Sclerosis-Related Factors and Mammography Screening Adherence

There are unique factors that can affect mammography screening adherence in women with MS as compared to the general population. Clinical progression of the disease can include changes in mobility and mental status change. In addition, depressive symptoms have been documented in this population, which may further complicate motivation for mammography screening.

2.3.3 Mobility/Physical Impairment in MS

Mobility restriction is a common physical disability among individuals with MS (Chan and Heck, 2000). Factors affecting mobility include: 1) fatigue, 2) cognitive impairment, 3) psychological perspective, 4) sociocultural factors, 5) environmental factors, 6) political factors, and 7) economic factors.

Weinshenker, Bass, Rice, and Noseworthy (1989) measured the amount of time between onset of MS and the need for ambulatory aid using the Expanded Disability Status Scale (EDSS). The EDSS (Kurtzke, 1961) is currently considered the most useful clinical measure of MS disability level (Appendix E). The scale ranges from zero to ten with zero equaling no impairment and ten equaling death due to MS. EDSS scores of four and lower provide an indication of a minimal mental status change. A score of higher than four is an indication of locomotion disability (Freeman, Langdon, Hobart, & Thompson, 1997), a score of six indicates that the individual requires the use of a unilateral ambulatory aid (Kurtzke, 1983), and at a score of eight, the individual requires a wheelchair for mobility. Weinshenker et al. (1989) reported that the median time from onset of MS to reach a score of six was 15 years. A score of 3.1 on the EDSS was used as an inclusion criterion when investigating 60 patients with MS (mean

age=44.5 years). It was found that 58.3% of the patients gave up their jobs, 8.3% had a change in marital status, 41.7% had disruptions with family due to the inability to provide care for themselves, 68.2% had problems with social relationships, 43.3% needed economic support, and 80% had episodes of emotional distress. Mobility in MS is more than just a physical problem for the patient. It also has implications for society including inability to complete family roles or the ability to function in some occupational capacity.

2.3.4 Mental Status Change in MS

Mental status changes are also evident in patients with MS. Approximately 50% of patients with MS experience mental status changes (Beatty, 1993; DeLuca, Johnson, & Natelson, 1993; Rao, 1995). MS-related cognitive impairment was also reported in 43% of members of a large, community-based MS Society (Rao, Leo, & Ellington, 1991), and 59% of a large clinic-based sample (Heaton, Nelson, Thompson, Burks, & Franklin, 1985). Daly, Komaroff, Bloomingdale, Wilson, and Albert (2001) compared cognitive function in patients with chronic fatigue syndrome, multiple sclerosis, and depression as well as healthy controls. The subsample of 24 MS patients (specifically with relapse-remitting type) with a mean age of 39.6 years was given a neuropsychological battery along with the other subgroup. The battery measured the cognitive dimensions of verbal fluency, spatial ability, attention, language, executive function, and Intelligence Quotient (IQ). Results revealed mental status changes with cognitive impairment in all three patient groups, although the prevalence was greatest in the depression subsample (F=2.87, p<.001). Post hoc Analysis of Variance of all three patient groups showed impairment with memory in comparison with the healthy controls.

Rao, Hameke, McQuillen, and Lloyd (1984) also found significant findings with memory disturbance in chronic progressive MS ($p<.05$ in all three memory tests used). Additionally, Amato, Ponziani, Siracusa, and Sorbi (2001) found in a reappraisal of the same sample after 10 years that those previously shown to have cognitive defects had emergence of deficits in attention and short-term spatial memory. The degree of physical disability, progressive disease course, and older age were predictive of the extent of cognitive decline. A comprehensive neuropsychological evaluation in 42 patients with Alzheimer's disease and an equal number of patients with chronic progressive MS revealed that Alzheimer's disease was associated with relatively greater impairment of learning, memory, and verbal skills, whereas the MS group showed more impairment in attention, incidental memory, and psychomotor function.

2.3.5 Depressive Symptomatology in MS

Depressive symptoms have also been documented in this population. Ten years after baseline assessment, a replicated prospective study assessed 27 adults with MS for physical disability, cognitive status, negative life stress, coping strategies, and depressive symptoms (Aikens, Fischer, Namey, & Rudick, 1997). After accounting for cognitive status and disability, life stress was positively correlated with current and future depressive symptoms. In addition, Bakshi et al. (2000) assessed fatigue in patients with MS and the relationship between fatigue (measured by the Fatigue Severity Scale), depression (measured by the Hamilton Depression Rating Scale and Beck Depression Inventory), and neurologic disability (measured by the Expanded Disability Status Scale). The Hamilton and Beck depression scores were significantly correlated with MS fatigue ($p=.008$), and depression severity correlated with fatigue after controlling for disability ($rho=0.37$, $p=.02$).

Arnett, Higginson, and Randolph (2001) compared the performance of depressed and nondepressed MS patients on an effortful planning task (Tower of London) to evaluate if planning impairments in MS patients were associated with depression. Greater scores on the Tower of London indicate poorer performance. Compared with nondepressed MS patients, depressed MS patients made significantly more moves and took more time per trial on the planning task ($p<.05$). These findings suggest that slowed information processing speed and deficient nonspeeded central and executive skill may be core to the cognitive deficit characteristics of depressed MS patients. Finally, the Structured Clinical Interview for DSM IIIR was administered to 221 MS patients. The rate and lifetime risk of depression for cases were calculated using the product limit estimate of survival function. Index cases had a 50.3% lifetime risk of depression.

Diaz-Olavarrieta et al. (1999) found neuropsychiatric symptoms present in 95% of patients (N=44) with MS, compared to only 16% of control subjects (N=25). In addition, depressive symptoms were present in 79% of patients. Depressive symptoms of sufficient severity and duration to warrant a diagnosis of major depression affect up to half of patients with MS during the course of their illness (Sadovnick et al., 1996). This is three times the prevalence reported for major depression and psychiatric comorbidity in community-based samples, and exceeds that for other neurological disorders (Schiffer & Babigian, 1984).

While detection of brain lesions by magnetic resonance imaging has been shown to correlate with mental status changes in MS, depression has been more elusive. Evidence for increased social stressors and inadequate family and community support suggests that depression in MS has a complex, multifactorial pathogenesis.

2.4 SUMMARY

In summary, it is known that barriers exist in women in the general population as well as those with disabilities when trying to obtain screening for breast cancer with mammograms. Treatment for MS may also place the person at greater risk for cancer. In addition, women with MS have specific disease-related barriers that prevent adherence to mammography screening, specifically physical impairment, mental status changes, and depressive symptomatology. It is unclear what specific unique barriers exist for mammography screening for women with MS as compared with women in the general population. In addition, a specific conceptual framework has not been employed to empirically guide research in breast cancer screening behaviors in women with MS.

The following gaps exist in knowledge of mammography screening adherence among women with MS:

1. No studies have documented adherence to mammography screening and specific variables related to why women with MS do not receive mammograms.
2. The EHBM has not previously been used to guide research regarding breast cancer screening behavior in this population. Studies have not identified perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, or modifying factors as potential predictors of mammography screening in this population.
3. No studies have documented adherence to mammography screening in homebound women with MS who receive an intervention to promote mammography screening by the NMSS.

Therefore, an investigation was proposed to examine the relationship between variables of the EHBM (perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors) and adherence to mammography

screening in homebound women with MS who receive a NMSS intervention. Inclusions of these variables will assist in bridging the gaps found in the literature review.

3.0 METHODOLOGY

This chapter provides a detailed description of the methodology applied for an investigation of the relationship between variables of the EHBM and adherence to mammography screening. The study design, sample, setting, and instrumentation for measuring EHBM variables are described. The procedures for data collection and the plan for data analysis are outlined. Data and safety monitoring and human subject issues are discussed.

3.1 DESIGN

This study used a correlational, descriptive design to aid in gaining more information about predictors of mammography screening adherence in a sample of women with MS who are homebound. The EHBM was used as the conceptual framework for this study. The EHBM variables, including perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors, were the independent variables. The dependent variable was adherence to mammography screening (Appendix D).

Subjects were interviewed and completed measures after they participated in an intervention of the Home-based Health Maintenance Program for Women with MS. This program used a new approach involving a home-based visit by a nurse midwife who delivered care related to breast and gynecologic screening in a population of disabled homebound women

(ages 40-70 years) with MS. Nurse midwifes have been increasingly addressing issues of health care in women of all ages across the lifespan (McCool, 1994).

3.2 SAMPLE

Mammography screening adherence 2 months after the home visit with the nurse midwife s ascertained by accessing the data set at the NMSS. Adherence with mammography screening was recorded in this data bank. The sample for this study was derived from a larger intervention study conducted by the Allegheny District of the NMSS, which has identified approximately 2,000 people with MS living in Allegheny County. Of these, 1460 (73%) were women. The NMSS completed a literature review, and found that 18% of all persons with MS are homebound (262 in this population, 7%) due to significant disability resulting from neurological impairments of the disease (NMSS, 2001). The local MS Society chapter of the NMSS approached 250 homebound women for participation in their intervention program, which consisted of the following:

1. Underserved, homebound women with MS in Allegheny County who have not received regular breast and gynecologic care were identified through a NMSS database.
2. Women received a home visit by a nurse midwife that included acceptation of age, history of physician recommendation for mammography, history of mammograms, and smoking behavior as well as performance of a clinical breast exam, pelvic exam, and pap test, and completion of the MMSE.
3. Women and their partners were taught self-breast exam techniques. At this time, written material was provided to reinforce the teaching session.

4. The nurse midwife scheduled a mammography appointment for each woman with MS, arranged transportation, and assisted with health insurance procedures. The nurse midwife identified accessible mammography sites that employed staff proficient in assisting and operating mammography machines when alternative positioning was required. The test was scheduled within one month of the home visit.

The original intent of this dissertation study was to obtain a total sample size of 150 women (as determined statistically) who would be recruited among those receiving the NMSS intervention program. The sample size of 150 was to achieve 80% power to detect a standardized difference between adherent vs. non-adherent of d=.46 between population EHBM variables assuming a group standard deviation of 1.0 with a significance or alpha level of .05 using a two-sided two sample t-test. It was anticipated that the larger NMSS intervention program would have already completed the intervention with approximately 100 women at the time of the initiation of the dissertation. It was anticipated that the distribution of adherent to non adherent subjects in the sample would be equal.

3.2.1 Subjects

The local chapter of the NMSS began home visits to implement their intervention in November 2001. Anecdotal conversations with the NMSS confirmed that the best modality for an intervention in this sample in face to face teaching. These efforts continued up until October, 2004. All of the women had MS and required wheelchair utilization. A total of 149 women were approached to participate in the NMSS program. One-hundred and eight (72%) consented to a home visit and mammography referral to Magee Women's Hospital Breast Cancer Program,

which is specifically designed to accommodate women with disabilities. Data collection for the dissertation study began in January 2004.

After nine months of data collection, 24 women had consented to participate in the dissertation study, 13 were found ineligible due to lack of participation in the intervention. A final sample size of 11 women was obtained (Figure 1). These 11 women were among the 108 women who participated in the NMSS intervention. Since a small sample size was obtained for the dissertation study, a secondary analysis was undertaken on data from the 108 women who had received the NMSS intervention. After IRB approval was obtained for a modification of the study, the NMSS provided de-identified data from their Intervention Program for the secondary analysis.

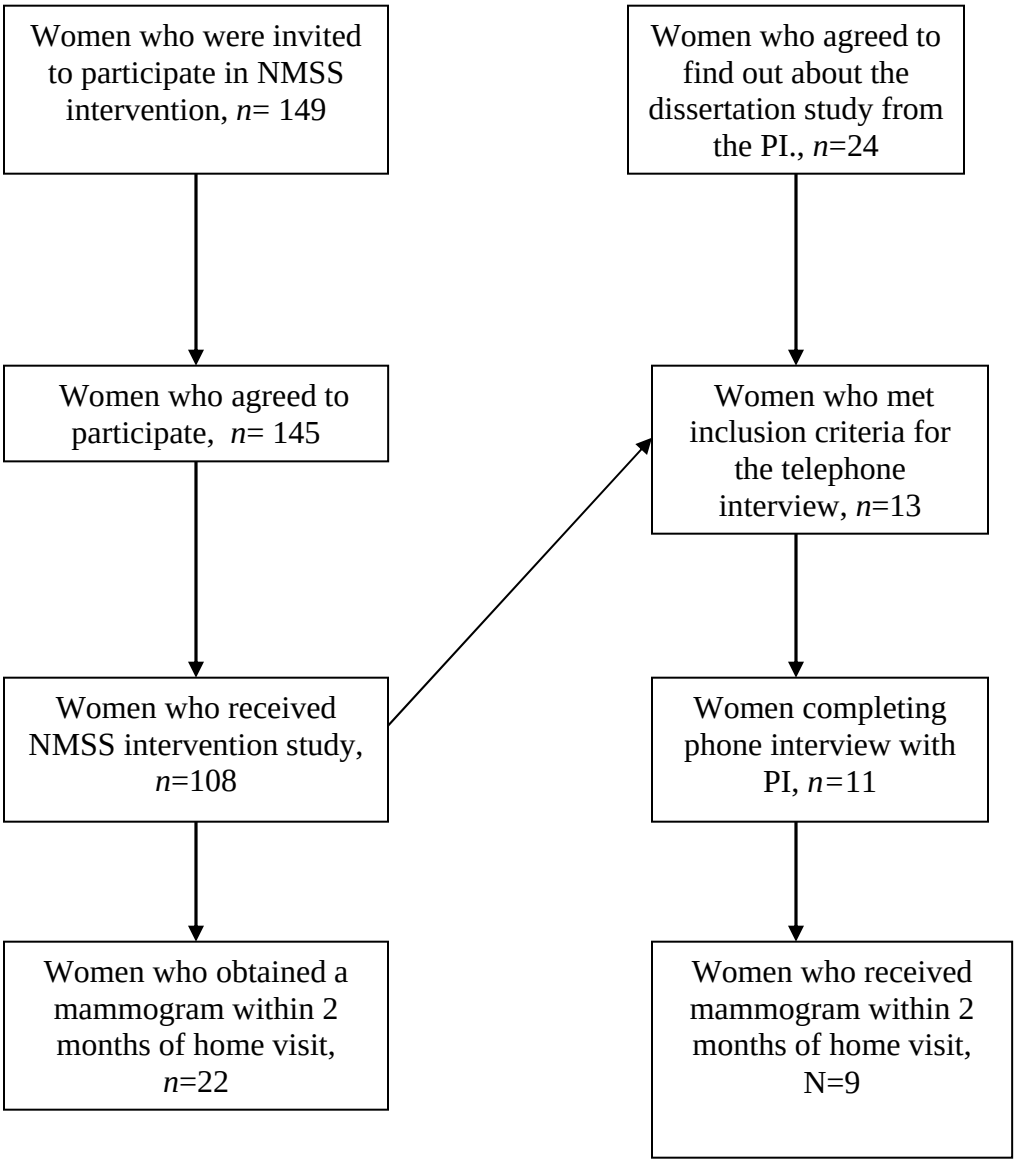


Figure 1: Synthesis of Subject Attrition

The NMSS de-identified data included:

1. Date of previous gynecological exam and physician mammogram referral
2. Date of home visit
3. Date the actual mammogram was completed
4. The results of the mammogram
5. Smoking history
6. Wheelchair utilization

From these data, aspects of the EHBM, including perceived barriers (wheelchair utilization), cues to action (physician referral), and modifying factors (smoking), were further analyzed with descriptive and correlation statistics. The aims of this secondary analysis were to:

1. Describe the population of women who chose to participate versus not to participate in the intervention study.
2. Determine the number of women who participated in the mammography screening with removal of perceived barriers.
3. Determine the number of women who have had a physician referral for a mammogram in the year prior to receiving the intervention.
4. Determine the number of women who were diagnosed with breast cancer as a result of the screening mammogram.
5. Determine if there is a correlation between the modifying factor (smoking) and adherence to mammography screening.

Due to this change in the research design, the analysis was divided into two phases. Phase One is the secondary analysis of the de-identified data obtained from the Home-based Health Maintenance Program for Women with MS collected by the NMSS. Phase Two is an analysis of

the EHBM variables collected from the sample of 11 women who received the intervention from the NMSS as part of the original dissertation design.

3.2.1.1 Inclusion criteria (Phase Two)

Included were women who were:

1. Homebound with MS as defined by the Home-based Health Maintenance Program for Women.
2. Able to carry on meaningful conversation without evidence of disorientation or confusion as assessed by the MMSE score of 21.
3. At least 40 years of age.

3.2.1.2 Exclusion criteria (Phase Two)

Excluded were women who:

1. Had an underlying psychiatric diagnosis other than depression as confirmed by subject self-report.
2. Did not have or were unable to use a phone.

Eligibility was established by the NMSS using a checklist prepared by the principle investigator that was completed by the midwife following delivery of the Homebound Health Maintenance Program.

3.2.2 Setting

Data were collected on the women with MS in Phase Two via telephone interview following completion of the home visit intervention by the midwife. The interview took place at a

prearranged time at the woman's convenience. The participant was able to discontinue the interview at any time.

3.3 METHODS

3.3.1 Measures

Specific instruments used to measure the EHBM variables in Phase Two are discussed in this section. The specific variables measured include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors.

3.3.2 Susceptibility/Severity-Breast Cancer Knowledge Test

Perceived susceptibility and severity were measured by the Breast Cancer Knowledge Test (BCKT) (Stager, 1993). The BCKT also assesses screening and detection knowledge regarding breast cancer (Appendix J). The test takes 6 minutes to complete. The BCKT is a paper-and-pencil test with true and false responses that evaluates one's knowledge base of breast cancer risks. The score is calculated as a percentage of 20 questions answered correctly, including the two subscales of knowledge (susceptibility) and curability (severity). A previous study (McKance, Mooney, Smith, & Fields, 1990) identified that the mean knowledge score is negatively correlated with age (r=-.30, p=.001), and positively correlated with education (r=.33, p=.001).

The BCKT is derived from a larger questionnaire based on Rosenstock's (1974) HBM. Item content was based on a review of literature, and review by content experts for relevancy, adequacy, content validity, and wording of an item (McKance et al., 1990). Initial testing included interviews with 20 women. In addition, reliability was conducted initially on a convenience sample of 101 women aged 50 or older (McKance et al, 1990). Knowledge correlation coefficient (biserial correlation of item to total) was found to range from be .25 to .56. In addition, standardized alpha has been documented to be .60 for general knowledge and .62 for curability. No significant correlation was found between women's scores and frequency of use of mammography or professional exams. Dolan, Lee, and McDermott (1991) used the BCKT to assess age-related differences in breast cancer knowledge and perceived risk among women in a primary care setting. The BCKT had not been used previously with the MS population. For this dissertation, the knowledge and curability scales were used to measure the EHBM variables of susceptibility and severity, respectively.

3.4 BENEFITS

3.4.1 Benefits and Barriers Mammography Screening Test

Champion (1995) developed the Benefits and Barriers Mammography Screening Test a scale to measure Health Belief Model concepts of benefits and barriers. The subscale for benefits of this instrument was used to measure the variable of benefits in this study. Both scales use a summated Likert format with five response options, with 3 or above indicating knowledge of benefits. Data were collected on a random sample of 581 women who were 35 years or over.

Retest data were obtained 4-6 weeks later. Construct validity was established using exploratory factor analysis and confirmatory factor analysis with results confirming independence of constructs. Cronbach alpha reliability coefficients were 0.79 for the benefits scale and 0.73 for the barriers scale. The instrument has also been found to be culturally sensitive, as psychometric properties were identified in a group of African American women age 45 to 64 years of age (N=329). Cronbach alpha reliability coefficients ranged from .65 to .90, and test-retest reliability ranged from r=.40 to .68. The internal consistency reliability was later reported as .75 to .88, and test retest reliabilities ranged from .59-.72 (Champion, 1999).

3.5 BARRIER

3.5.1 Cost, Health Insurance Coverage

Cost was measured by health insurance coverage, and through any out of pocket expense that was accrued when obtaining the mammogram. Health insurance coverage was assessed as part of an investigator-developed questionnaire that measured health insurance coverage through a fill-in format, as well as any other possible barriers including transportation costs or time off work by a primary caregiver who accompanied the subject. Most of the subjects had Medicare as their insurance carrier due to their disability.

3.5.2 Inconvenience/Physical Impairment, Short Form-36

Physical impairment was measured with the Short Form-36 (SF-36) a 36-item questionnaire designed for use in clinical practice and research, health policy evaluations, and general population surveys (Ware & Sherbourne, 1992). The SF-36 assesses eight health concepts (Appendix G):

1. limitations in physical activities because of health problems
2. limitations in social activities because of physical or emotional problems
3. limitations in usual role activities because of physical health problems
4. bodily pain
5. general mental health (psychological distress and well-being)
6. limitations in usual role activities because of emotional problems
7. vitality (energy and fatigue)
8. general health perceptions

Scoring is a two-step process. In step one, precoded numeric values are recoded per a scoring key. Each item is scored on a 0-100 range so that the lowest and highest scores are set at 0 and 100, respectively. Scores represent the percentage of the total possible score achieved. In step two, items in the same scale are averaged together to create the eight subscale scores.

Validity and reliability of the SF-36 has been reported (Brazier et al. 1992). A sample of 1,980 patients aged 16-74 years in the general population were randomly selected to examine scores and response rates for each health dimension subscale. The response rate was high (83%). Evidence was found for internal consistency reliability with Cronbach's alpha greater than .85 and test-retest reliability coefficients greater than r=.75 for all dimensions except social

functioning. Construct validity was found to be evident by distinguishing groups with expected health differences. The SF-36 was able to detect low levels of ill health in patients who had scored 0 (good health) on the Nottingham Health Profile, which was used for comparison.

Furthermore, the SF-36 has satisfied rigorous psychometric criteria for validity and reliability in a broad sample (*N*=1,310) of patients suffering from four common clinical conditions (Garratt, Ruta, Abdella, Buckingham, & Russell, 1993). Clinical validity was shown by the distinctive profiles generated for each condition, which differed from that in the general population in a predictable manner. In addition, SF-36 scores were lower in referred patients with a clinical condition than in patients not referred (healthy population) and were closely related to general practitioners' perceptions of severity. Lyons, Perry, and Littlepage (1994), also found evidence for a high degree of reliability with Cronbach's alpha statistic exceeding .80 for each subscale.

3.5.3 Depressive Symptomatology, Beck Depression Inventory II

Depressive symptomatology, a potential barrier to adherence to mammography screening, was measured with the Beck Depression Inventory, 2nd edition (BDI-II, Beck, Steer, & Brown, 1996), a 21-item test with a Likert scale that has responses ranging from 0=least amount of agreement to 3=most amount of agreement to the statement (Appendix F). Subjects are asked to best describe how they have been feeling during the past two weeks, including that day (see Appendix F). The score is obtained by summing the responses to the 21 items. The maximum score is 63. Scores of 0-13 indicate minimal depression, 14-19 indicate mild depression, 20-28 indicate moderate depression, and 29-63 indicate severe depression. The test is easy to administer orally, and takes 5 to 10 minutes to complete.

During the last 35 years, the BDI has become one of the most widely used instruments for screening for possible depression in diagnosed psychiatric patients and in normal populations as well (Piotrowski & Keller, 1992). The BDI-II indicates the presence and degree of depressive symptoms consistent with the DSM-IV.

Two comprehensive reviews concerning the BDI's applications and psychometric properties across clinical and nonclinical populations have reported its high reliability (Beck, Steer, & Garbin, 1988). Reliability has also been established with a psychiatric outpatient sample (N=500) and a college student sample student (N=120). All of the corrected item-total correlations for the 21 BDI-II items for both samples were significant beyond the .05 level of a one-tailed test.

Validity has been established with correlations obtained between BDI-II total scores and other psychological tests. In addition, prior factor analyses have indicated that the BDI-II reflects highly correlated factors (Beck Steer, & Garbin, 1988). Diagnostic discrimination also has been established through a one-way ANOVA with varying outpatients diagnosed with five types of mood disorders consistent with the DSM-IV [$F(4,259)=4.93$, $p<.001$] as documented by Beck et al. (1996). All of these measurements assist in establishing content and construct validity.

In this study, a total depression score was obtained for each subject. The instrument has been used this way especially with the other chronic disease populations (Beck et al., 1996), but it has not been used widely in persons with MS, as has been the Centers for Epidemiologic Studies-Depression (CES-D) Scale.

3.5.4 Mental Status Change

Mental status change was measured by the Mini-Mental State Examination (MMSE, Folstein, Folstein, & McHugh, 1975). As a clinical instrument, the MMSE has been used to detect impairment, follow the course of an illness, and monitor response to treatment (Appendix H). The test takes about 5 minutes to administer and can be administered by personnel with minimal training. The total score possible is 30. If the person answers the question incorrectly, then it is assigned a score of zero. Conversely, if the person answers correctly, then the response is assigned a score of one. The lower the total score, the higher level of mental status change.

The MMSE has also been used as a research tool to screen for cognitive disorders in epidemiological studies and to follow cognitive changes in clinical trials (Cockrell & Folstein, 1988). While the MMSE has limited specificity with respect to individual clinical syndromes, it represents a brief, standardized method to grade cognitive mental status (Anthony, LeResche, Niaz, VonKorff, & Folstein, 1982). It assesses orientation, attention, immediate and short-term recall, language, and the ability to follow simple verbal and written commands. It provides a total score that places the individual on a scale of cognitive function.

A total of 18,056 adult participants were selected by probability sampling from census data. It was found, through summary scores, that there was an inverse relationship between MMSE scores and age, ranging from a median of 29 for those 18 to 24 years of age, and 25 for individuals 80 years of age and older. The median MMSE score was 29 for individuals with at least 9 years of schooling, 26 for those with 5 to 8 years of schooling, and 22 for those with 0 to 4 years of schooling.

The MMSE has been used with the MS population. Beatty and Goodkin (1990) evaluated the MMSE as a screening test for identifying cognitive impairment in patients with

MS. In this study, patients with clinically definitive MS (*N*=85) also received an extensive battery of neuropsychological tests. The scores on the MMSE were negatively correlated with the number of neuropsychological tests on which patients with MS displayed impairment, yet the MMSE was a useful predictor of focal cognitive impairment, especially with relapsing-remitting patients. In addition, a correlational study of dementia, neuropsychological, and MRI findings in MS (Tsolaki et al., 1994) revealed that patients with MS are impaired in a broad range of cognitive functions but primarily in the dimension of memory. The number of lesions in the corona radiata, insula and hippocampus is correlated with the level of cognitive impairment, and enlargement of the third ventricle is an indicator of memory impairment, which is evident in patients with MS.

Validity has been previously established for the MMSE. Three diagnostic subsamples (with the cutpoint at 24) revealed that out of a total score of 30, the mean score for patients with dementia was 9.7, depression with cognitive impairment was 19.0, and uncomplicated affective disorder with depression was 25.1. The mean score for normal subjects was 27.6, thus the scores agreed with the clinical presence of cognitive difficulty. As the cognitive difficulty is usually less in depression than in dementia, the scores dispersed in a fashion that is consistent with the severity of the difficulty (Folstein et al., 1975). MMSE scores were also examined in 137 consecutive psychiatric admissions. The mean score for dementia was 12.2, affective disorder depressed was 25.9, mania was 26.6, schizophrenia was 24.6, personality disorder with drug abuse was 26.8, and neuroses was 27.6.

Concurrent validity has been determined by correlating MMSE scores with the Weschler Adult Intelligence Scale (WAIS), both completed in the same week. The MMSE was associated with the WAIS verbal Intelligent Quotient (IQ); Pearson correlation coefficient was 0.78

(p<.001). Dick et al. (1984) obtained Spearman correlation coefficients between the MMSE and WAIS IQ scores in 30 patients and found that for verbal IQ the correlation was r=.45 (p=.02) and for performance IQ the correlation was r=.58 (p=.004). This finding reflects a moderate positive relationship between the verbal IQ and neuropsychological impairment as measured by the MMSE.

Inter-rater reliability of the MMSE scores has been tested (Pangman, Sloan, & Guse, 2000) using the Wilcoxon signed rank test, which found no differences between two total MMSE scores of 15 cases tested by different observers in an interval of 24 hours. This was also true for the cases tested by the same observer at a 24-hour interval, and for the 14 clinically stable patients rated by the same observer at a mean interval of 31 days (range 7-70 days). Test-retest reliability evaluated with Kendall correlation coefficients was .65 for the group retested by the same observer and .63 for the group retested by different observers. Folstein et al. (1975) has previously reported Pearson correlation coefficients of .92 for patients retested by the same observer and .95 for patients retested (over a 2-week time period) by a different observer.

3.6 CUES TO ACTION-PHYSICIAN RECOMMENDATION

The investigator-developed questionnaire contained an item to assess whether physicians recommended mammography screening. Each subject was asked: “Has your physician recommended a mammography to you in the last year?” If the subject responded affirmatively, she was asked to further delineate whether the physician was a primary care physician, neurologist, or gynecologist.

3.6.1 Self-Efficacy-Mammography Screening Self-Efficacy Scale

The Mammography Screening Self-Efficacy Scale (MSSS) was developed to measure women's self-efficacy in relation to mammography screening behavior. The MSSS measures the strength and generality of women's efficacy expectations in relation to mammography screening behavior (Matthews, 1997). The instrument has 36 items that assess womens' perceptions of the likelihood of obtaining a mammogram within the year in relation to varying levels of prompts and barriers to mammography screening. Responses are arranged on a Likert scale from 0 (=not at all likely) to 10 (=very likely). Total scores range from 0 to 360, which is the summation of all items. Test-retest reliability within a 2 week time period demonstrated Cronbach's alpha of .99 for both time periods with administration of the instrument in a group of women (ages 42-69). Intraclass coefficient of reliability was .86.

3.6.2 Modifying Factors-Education, Age, and Race

The modifying factors of educational attainment, age, and race were also measured in the investigator-developed questionnaire. The choices were in multiple choice format except for age which was a continuous variable completed in a fill-in format by asking the question "How old are you?" Race was obtained by asking the person: "What is your race?" and was part of the questionnaire as well.

Education level was assessed as part of the investigator-developed questionnaire using multiple choice format. The choices included the highest education achieved including less than high school, high school, technical school, college, graduate, and doctorate.

3.6.3 Post-Intervention Mammography Screening Adherence

Adherence to mammography screening, the outcome variable, was measured by obtaining data from the NMSS data bank as to whether or not the subject chose to get the scheduled mammogram. The time period for this measurement was within 2 months after receiving the intervention.

3.7 PROCEDURE

Approval was obtained from the University of Pittsburgh Institutional Review Board. The investigator received a list from the NMSS of Allegheny County that identified women who were interested in receiving a phone call from the principal investigator (PI) about this study after completing the NMSS intervention, the eligibility checklist, and screening with the MMSE. Women who wished to learn more about the study were given a consent form by the NMSS. The PI called these women and explained the study, answered any of their questions, and determined their interest in participation. Written informed consent forms were obtained via mail prior to this, and the consent form reviewed at this time. If the woman agreed to participate, a telephone visit was then scheduled at the subject's convenience. The phone visit started with questions regarding the demographic variables of educational level, age, race, and health insurance coverage (for cost). The Breast Cancer Screening Knowledge Test, the SF-36, the BDI-II, the Benefits and Barriers Mammography Screening Test, and the Mammography Screening Self-Efficacy Scale were then administered. Finally, the woman was questioned to determine whether her physician (either the primary care provider, neurologist, or gynecologist) had recommended a

mammography in the last year, and any specific barriers she may have encountered when trying to obtain one. The battery took approximately 45 to 60 minutes to administer. Two months later, the PI determined whether subjects adhered to the mammography screening by querying the data base at the Allegheny County Chapter of NMSS.

3.8 DATA MANAGEMENT AND SCREENING ANALYSIS

3.8.1 Data Management

All statistics were computed using the Statistical Package for Social Sciences (SPSS) version 10.0. The data were organized with researcher-developed forms. The data were screened verified as the forms were collected. Data was manually inputted into the computer. Data were verified by the PI. Excel data management software was used to store all the raw data.

All subject data were kept together in one folder until analysis was begun. The subject code was written on each form. Each subject was allocated her own file folder in a cabinet only accessible to the PI. Data were entered into the computer as soon as possible after collection to prevent loss of valuable data.

Prior to data entry, data were carefully checked for any potential problems to keep the data entry process as precise as possible. All data were corrected for errors prior to entry. The potential for errors was limited in that data collection occurred through a one-on-one personal interview. Therefore, there were no missing data, the subject did not respond with two answers when only one was required, no items were marked between two response options with the Likert scale, and no write-in information was obtained.

Data entry was completed by the PI. After data entry of each subject, backup of the database occurred through storage on floppy disks. All data were then checked, verified, and double checked for accuracy.

All data were stored for seven years after the study is completed, including raw data and the database. The PI will store the data in an office with a double-locked cabinet to prevent free access to the information without the investigator's permission.

3.8.2 Data Screening

3.8.2.1 Descriptive statistics

Descriptive statistics were computed on all variables including graphical representation, range, and contingency checking. Data were summarized as frequency counts and percentages. Levels of measurement (nominal, ordinal, interval, or ratio levels) were determined for all variables. For continuous variables, measures of central tendency (including mean, mode, and median) and measures of dispersion were computed (including standard deviation, variance, and range). Finally, the shape of the distribution was assessed for skewness and kurtosis. Descriptive statistics were computed as part of preliminary data analysis.

Preliminary data analysis included appraisal of data accuracy, detection of outliers, evaluation of underlying assumptions, application of data transformation as needed, and assessment of multicollinearity and missing data. Accuracy of the data was proofread through visual verification with the original data against the computerized data file in the data window.

Outliers were to be detected through frequency statistics. Univariate outliers were to be identified through inspection of histograms and graphs, including boxplots and normal probability plots. Continuous variable outliers were to be found through probability statistics.

The outliers were then to be investigated through the creation of dummy variables, with 1 representing the outlier(s), and 0 otherwise. The dummy variable was to be treated as the dependent variable, and discriminant function analysis or logistic regression was to be completed. The means of these variables were to be computed for outlying and nonoutlying cases. Further examination was anticipated, but due to the lack of outliers, the above plan was not implemented.

Underlying assumptions of normality were then evaluated. Multivariate and bivariate normality were considered first as categorized by adherence group. Normality was evaluated by measures of skewness and kurtosis, and graphical representation through frequency histograms. Independence was tested through scatterplots. Finally, homoscedasticity was evaluated graphically, and the assumptions were found to be met.

3.8.3 Data Analysis

3.8.3.1 Phase One

1. Are there differences in demographics between those women who chose to participate versus not to participate in the intervention study?

   Frequency and descriptive statistics were used to answer this research question. Due to the nature of the de-identified data, no analysis was performed.

2. If there was removal of perceived barriers, how many women would participate in the mammography screening?

   Frequency statistics only were used to answer the research question. Again, other analysis could not be performed.

3. How many women had physician referral for a mammogram in the year prior to receiving the intervention?

Frequency statistics only were used to answer the research questions.

4. How many women were diagnosed with breast cancer as a result of the screening mammogram?

Frequency statistics only were used to answer the research question.

5. Is there a relationship between the modifying factor of smoking and adherence to mammography screening?

Kendal's tau correlation analysis was performed. The analysis is more appropriate for small samples for which the distribution is not known. For analysis, smoking and mammography were dichotomized and coded with 0=no smoking and 1=yes smoking.

3.8.3.2 Phase Two

The research question for this phase was: Is there an association between perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors of breast cancer and post-intervention mammography screening adherence in homebound women with MS?

Each hypothesis involving the variables was analyzed. Binary logistic regression analysis was the primary data analysis procedure anticipated for answering all of the hypotheses. Predictors were divided into demographic/modifying variables, and attitudinal predictors, which are the EHBM concepts. The discrete outcome variable was adherence to mammography screening, or whether or not a mammogram was performed within 2 months of the intervention.

Since the sample size was so small, logistic regression coefficients were not performed. Instead, descriptive statistics only were used to establish a relationship.

3.8.4 Data and Safety Monitoring

Data were reported in aggregate for the group of subjects as a whole. Subjects were told that they could discontinue the phone interview at any time and withdraw from the study if they desire without penalty. There was no payment for participating in this study. There were minimal risks involved in the study procedures and no direct benefits to the participants.

The administration of the instruments to the subjects could have caused distress. Every attempt was made to avoid extreme upset or distress. The subjects were given the option to terminate the session at any time.

All subjects were informed about the study and provided written informed consent. All subjects were assigned a designated number to ensure confidentiality. Informed consent forms were stored in locked files and all data were coded so that identification of an individual's data file could only be made with use of a master list. This list was secured as well and was available only to the principal investigator. All data were stored in a locked filing cabinet and were only accessible by the principle investigator.

3.8.5 Human Subjects

Women were only recruited to this study in light of the primary variable of mammography screening. Men were not eligible due to the fact that male breast cancer accounts for only 1% of the disease in the U.S. and the natural history of the disease differs from the natural history of the

breast cancer in women. There were no exclusion criteria based on race or HIV status. Children were not recruited because of the rare occurrence of MS in children and age restrictions in the primary study.

4.0 RESULTS

4.1 PHASE ONE

4.1.1 Research Questions

Research Question #1: Are there differences in demographics between those women who chose to participate versus not to participate in the intervention study?

De-identified data of the women who were invited to complete the intervention program (*n*=145) who agreed to participate in the NMSS intervention program were descriptively analyzed. Out of those 149 women, 108 women actually received the intervention. Thirty-nine of the 41 (95%) who refused the intervention identified lack of time for the commitment; one women (2.5%) was found to be "too depressed," while another (2.5%) suffered mental status changes that would likely interfere with learning and retention of new information.

Of the 108 who received the NMSS home-based intervention, all required wheelchair utilization and were indeed homebound. Only one (.9 %) woman reported a previous history of breast cancer. During the three-year period during which the intervention program took place, four women (4%) did not complete the whole intervention due to their subsequent death. No other demographic variables or characteristics were available for analysis.

Research Question #2: If there was removal of perceived barriers, what percentage of women would participate in the mammography screening?

It was assumed that perceived barriers were removed since the cost was covered for the visit by the NMSS, free transportation was provided, and an appointment in a mammography center that is accessible to those who are disabled was made. Of the 108 women who received the home-based intervention, 15 (14%) had received mammograms at their follow-up visit within 2 months of their initial home visit. Only 7 (6.5 %) women stated that they had a mammogram in the previous year. None of these 7 (6.5 %) were among part of the 15 women who did receive a mammogram at the 2 month follow-up visit. Thus, 86 (80%) did not adhere to mammography screening.

Research Question #3: How many women had physician referral for a mammogram in the year prior to receiving the intervention?

Only 7 (6.5 %) women stated that they had a mammogram in the previous year as documented on the NMSS data base. One participant stated to the midwife that her physician felt that a mammogram was not needed for her, even though she had not received a previous baseline mammogram or gynecological examination.

Research Question #4: How many women were diagnosed with breast cancer as a result of the screening mammogram?

Out of the women who did receive a mammogram (*n*=15) as a result of the intervention, two (13%)had positive results that required additional evaluation. A follow-up ultrasound was subsequently negative for one woman, while the other had a breast biopsy performed that was also negative for cancer. Therefore, none of the women were diagnosed with breast cancer as a result of the screening mammogram.

Research Question #5: Is there a relationship between the modifying factor of smoking and adherence to mammography screening?

Of the women who participated in the intervention (*n*=108), 23 smoked (21%). Of those who smoked, two (8%) received mammograms. Therefore, smokers accounted for only 13% of the 15 who received a mammogram.

For analysis, smoking and mammography were dichotomized and coded with 0=no smoking and 1=yes smoking. A correlation statistic between smoking and adherence was not significant when using a Kendall's tau (*r*=-.078, *p*=.05). Kendall's tau was the most appropriate statistic to examine the relationship in this small sample that was not necessarily normally distributed. In addition, a Fisher's Exact Test two-sided was not significant at .518, or even one-sided at .334. Thus, there was no significant relationship between the modifying factor of smoking and adherence to mammography screening in this sample.

4.1.2 Summary

The de-identified data supplied by the NMSS had little to no demographic information available regarding those who did or did not participate, since it was not predetermined to be collected. A

total of 108 women received the intervention program. Only 7 women had a mammogram within the last year, none were among the 15 who 2 months post-intervention had obtained a mammogram. None of the women who received the mammogram were diagnosed with breast cancer. In addition, it was found that there is not a correlation in this sample between the modifying factor of smoking, and mammography screening adherence.

4.2 PHASE TWO

The research question for this phase of the study was: Is there an association between susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, and modifying factors of breast cancer and post-intervention mammography screening adherence in homebound women with MS?

The purpose of the second phase of the dissertation study was to gain more information via interviews about predictors of mammography screening adherence in a sample of homebound women with MS who received the NMSS intervention. The interview was performed with women who met the inclusion criteria of the dissertation study and were willing to be interviewed (n=11). All of the women completed the phone interview, some using a speaker phone due to their inability to hold the receiver. The time required for interview completion was 45-60 minutes.

Prior to administration of the instruments, demographic data were obtained, including level of education, age, race, and health insurance, whether a mammogram was recommended in the last year and any barriers that prevented them from receiving a mammogram. The age range was 40-70 years, with a mean of 48 years, (SD 9.38). Table 2 reports the descriptive statistics for

the demographic and other variables. Hypothesis testing could not be formally completed due to sample size constraints.

Table 2: Summary of the Investigator Developed Questionnaire Responses (N=11)

Responses	n (%)
RACE	
White	10 (90.9)
African American	1 (9.1)
EDUCATION	
High School	3 (27.3)
College	6 (54.5)
Graduate School	2 (18.2)
HEALTH INSURANCE	
Private	8 (72.7)
Medicaid	1(9.1)
Medicare	2 (18.2)
RECOMMENDED MAMMOGRAM IN LAST YEAR	
Yes	7 (63.6)
No	4 (36.4)
WHO RECOMMENDED THE MAMMOGRAM	
Primary Care Physician	5 (45.5)
Gynecologist	2 (18.3)
Neurologist	1 (9.1)
None	3 (27.3)
BARRIERS TO MAMMOGRAM	
Yes	2 (18.2)
No	9 (81.8)
BARRIERS IDENTIFIED	
Physical impairment	1 (9.0)
Facility Access	1 (9.0)
None	9 (82.0)

The first two predictors of post-intervention mammography screening adherence analyzed in Phase Two of the study were perceived susceptibility and severity of breast cancer. The variables were both measured using the Breast Cancer Knowledge Test (BCKT). The scores ranged from 45% to 85%, with a mean score of 75%.

Descriptive statistics showed a *SD* of .1150, with a range of .40. Table 3 summarizes the responses.

Table 3: Summary of Incorrect Responses on the BCKT

Response	Total number of subjects with incorrect responses	(%)
SUSCEPTIBILITY		
A hard blow to the breast may cause a woman to get breast cancer	2	18
In some women, being overweight increases the risk of developing breast cancer	4	36
Some types of fibrocystic breast disease (noncancerous breast lumps) increase a a women's risk of breast cancer	6	55
Breast cancer is more common in 65-year-old women than in 40-year-old women	9	82
The most frequently occurring cancer in women is breast cancer	6	55
Women over age 70 rarely get breast cancer	4	36
SEVERITY		
By the time a cancerous breast lump is painful, it is too late to be successfully treated	3	27
Breast cancer is less likely to be cured in women with a family history of breast cancer	5	45

In this sample, there appears to be a positive relationship between susceptibility and severity and adherence to mammography screening as determined by the high percentage scores answered correctly, and the high number of women sampled who received a mammogram. A total of 9 of the 11 women interviewed did adhere to receiving the screening mammogram at the appointed time given, which was completed within the 2 month time period.

The third predictor of post-intervention mammography screening adherence analyzed was perceived benefits. Perceived benefits were measured by a subscale of the Benefits and Barriers Mammography Screening Test, with one indicating strong disagreement, two indicating disagreement, three indicating a neutral view, four indicating agreement, and five indicating strong agreement. The scores for benefits ranged from 51 to 100%, with a mean score of 75%. Therefore, 75% of the sample was able to identify benefits to mammography screening, by scoring an average of 3 or higher on the Likert scale. The data suggests that there may be an association between perceived benefits and adherence to mammography screening. The mean score was .7745, with a standard deviation of .1522. Table 4 summarizes the benefits the sample identified.

Table 4: Summary of Benefits Identified to Mammography Screening

Statement	Mean Score
When I get a recommended mammogram, I feel good about myself	3.09
When I get a mammogram, I don't worry as much about cancer	3.45
My doctor or nurse will praise me if I obtain the recommended mammogram	3.27
Having a mammogram or x-ray of the breasts will help me find lumps early	3.91
Having a mammogram or x-ray of the breasts will decrease my chances of dying from breast cancer	4.18
Having a mammogram or x-ray of the breasts will decrease my chances of requiring radical or disfiguring surgery if breast cancer occurs	4.18
Having a mammogram will help find a lump before it can be felt by myself or a health professional	4.09

The fourth predictor of post-intervention mammography screening adherence was perceived barriers. Cost (health insurance coverage) and inconvenience (facility access) were not found to be barriers to mammography screening as evidenced by demographic information obtained initially. A total of 81.8% (n=9) thought there were no barriers, and, of those, 18% (n=2) thought physical impairment and facility access were barriers. Other factors that were analyzed that may contribute to barriers included depressive symptomatology and mental status changes. Depressive symptomatology was measured by the Beck Depression Inventory, 2nd edition. To review, a score of 0-13 is minimal depression, 14-19 mild depression, 20-28 moderate depression, and 29-63 severe. The highest score indicated moderate depressive symptomatology (28), while the mean indicated minimal depressive symptomatology (13). Only one woman had moderate depressive symptomatology, the rest rated mild depressive symptomatology. Cognitive function was measured by the Mini-Mental State Examination, and none of the women were found to have mental status changes. Therefore, it can be deduced that cost, inconvenience, physical impairment, depressive symptomatology, and mental status changes were not a factor with adherence to mammography screening in this sample.

The fifth predictor analyzed was cues to action, as measured by physician recommendation. When specifically questioned, 63.6% of the 11 women interviewed had a mammogram recommended to them within the last year, mostly by their primary care provider. Even though this was more than half of the sample, none of the women had received a mammogram within the year prior to receiving the homebound intervention. Therefore, the data suggest that there may not be an association between physician recommendation and adherence to mammography screening.

The sixth predictor analyzed was self-efficacy, which reflects confidence in one's ability to perform mammography screening under varying conditions. The variable was measured using the Mammography Screening Self-Efficacy Scale (Matthews, 1997). All but two of the women planned on receiving a mammogram within the next year. One of woman who did not get a mammogram stated that no matter what factors were involved, she still would not get a mammogram because "it would not make any difference." Out of a possible 370 points, the mean score was 350. The higher the score, the more self-efficacy for mammography screening is evident. It was identified through this scale that cost was the main reason for not receiving a mammogram (unless the test was paid for 100%). Due to these high scores, it can be deduced that self-efficacy is a factor with mammography screening behavior in the sample of homebound women with MS.

The seventh and final predictor was modifying factors, which included educational attainment, age and race. The women were an average age of 56 years, and a majority of the sample was Caucasian (90.9%). All of the women graduated from high school, with 54.5% completing a four-year college education. An association between age and race cannot be determined due to the small sample size, and the fact that only one African American woman was interviewed. It can be deduced, however, that since these women were educated and did receive a mammogram, the data suggest that education is a factor of mammography screening adherence in this sample of homebound women with MS.

4.2.1 Logistic Regression Analysis

Binary logistic regression analysis was attempted. Due to the small sample size, the models were unattainable asymptotically despite univariate, bivariate, multivariate, and stepwise procedures employed.

Due to this limitation, the software package LogXact was then used. Not only can this software attempt binary logistic regression analysis with small sample sizes, but it can also analyze using both the asymptotic and exact approaches. Only self-efficacy was able to produce proper estimates and yield an odds ratio, which was not significant. The Fisher exact test was used to examine each of the predictors individually: susceptibility, severity, benefits, barriers and self-efficacy; all were nonsignificant.

Therefore, univariate binary logistic regression analysis using both asymptotic and exact estimation approaches was attempted, but models were not able to be estimated given the small sample size and the joint distribution of the data. The sparse cell sizes resulted in most odds ratios to be undefined.

Table 5: LogXact Findings of the EHBM Variables and Mammography Screening Adherence

	MUE	Exact (lower) Confidence Interval	Exact (higher) Confidence Interval
Susceptibility	1.50	--	5.17
Severity	1.50	--	5.17
Benefits	-0.41	--	2.26
Barriers	-0.60	-3.39	--
Self-Efficacy	1.52	--	5.75

MUE=Mean Upper Estimate

4.2.2 Summary

Due to the small sample size obtained in this study of women who were interviewed post-intervention, data were analyzed using descriptive statistics. Out of all of the variables of the EHBM, the data suggests that perceived susceptibility, perceived severity, perceived benefits, and self-efficacy are a factor of mammography screening adherence. Conversely, the data suggests that perceived barriers and cues to action are not a factor of mammography screening adherence. The data suggest that there may be an association between the modifying factor of education and mammography screening adherence, while physician recommendation, age, and race may not be related to mammography screening adherence.

5.0 DISCUSSION

The data suggest that variables of the EHBM (perceived susceptibility, perceived severity, perceived benefits, and self-efficacy) may be a factor of mammography screening adherence. The sample size of 11 homebound women with MS was a limitation.

5.1 EXPANDED HEALTH BELIEF MODEL

5.1.1 Susceptibility

A prospective study completed previously (Calvocoressi et al, 2004) found that across race, age, and family history of breast cancer, women who believed that their susceptibility was high were less likely to adhere to screening guidelines than women who believed that their susceptibility was moderate. The current study did suggest a relationship, however, between susceptibility and mammography adherence, but did not ascertain women's perceptions of susceptibility as high, moderate, or low.

Perceived risk, or susceptibility, has been a principle variable in theoretical models that attempt to predict the adoption of health protective behaviors (Katapodi, Lee, Facione, & Dodd, 2004). The findings of the study suggest that once again a relationship may exist between

perceived susceptibility and mammography screening adherence among homebound women with MS.

5.1.2 Severity

Holm, Frank, & Cutin, (1999), found that among women who participated in mammography screening, perceived seriousness or severity were not significant predictors of mammography behavior. Along with other model variables, Champion (1992) found that adherence with mammography screening adherence was influenced by perceived seriousness (or severity) of breast cancer. In addition, women adherent to mammography screening guidelines had significantly higher scores on seriousness Champion (1994). Findings in this study were more consistent with Champion's work.

5.1.3 Benefits

The results of this study are similar to those found by Champion (1999) who reported that the construct of perceived benefits were shown to be related to mammography screening. Both studies found that when knowledgeable of the benefits, the women chose to obtain the recommended mammogram.

5.1.4 Barriers

Major depression is estimated to strike between 25-50% of individuals diagnosed with MS at some point during their life as compared to the general population (2-14%), according to the

NMSS (2004). Depressive symptomatology as measured by the BDI-II in the current study, revealed that the level of depressive symptomatology overall was minimal, and the highest score obtained indicated moderate depression. Since the NMSS specifically stated major depression strikes those with MS, it would be expected that the women in this study would have had higher ratings. Unfortunately, no information was available as to whether these women were receiving antidepressants.

Additional MS-related factors of cost, inconvenience, physical impairment, and mental status changes did not appear to be related to adherence to mammography screening, contrary to what would be expected. Unfortunately, with the small sample size, it can only be suggested that a relationship does not exist. The literature review found that all factors have previously been associated with health screening behaviors.

5.2 CUES TO ACTION

Physician recommendation in the current study did not appear to be a cue to action related to mammography screening adherence. The finding opposes what MacDowell et al. (2000) found regarding women's willingness to obtain a mammogram when the physician recommended it. Similarly, Han et al. (2000) found that if a physician recommends it, women were six times more likely to obtain a mammogram.

5.2.1 Self-efficacy

The findings in the current study suggest that self-efficacy may also be related to mammography screening adherence in these women with MS. Matthews (1997) also found that "prior preventive health practices, wellness orientation, and community resource explained variability in current overall adherence to preventive health practices." In the current study, the community resource was the NMSS. However, self-report has also been shown overestimate adherence to health promotion guidelines in regards to mammography screening adherence when collected through phone interviews (Armstrong, Long, & Shear, 2004). In the current study, adherence was validated through the appointments kept at Magee Women's Center for the actual mammogram itself as found in the NMSS data set.

5.2.2 Modifying Factors

These factors are difficult to discuss due to lack of data from a small sample size and examination of direct effects only. The current study findings suggest that there may be a relationship between education and mammography screening adherence in the sample of women with MS. However, due to the small sample size, exploration of the role of modifying factors is limited to direct effects only. The age range of the women was 40 to 70 years, and only one woman was African American. Family history data were not gathered, so these demographic variables could not be specifically addressed. Additionally, previous studies have found that mammography screening peaked at age 55 to 59 years, and then declined (Jerant, Franks, Jackson, & Doescher, 2004). However, this disparity was not evident in this study, since the mean age was 48 years.

5.2.3 Mammography Screening Adherence

In the current study, 9 out of the 11 (82%) women adhered to the mammogram in the scheduled time of 2 months. However, differences as small as 1 month in the definition of screening intervals can produce differences in adherence estimates as large as 27% (Partin, Casey-Paal, Slater, & Korn, 1998). A mailed and telephone reminder was shown to result in greater adherence to mammography screening (Saywell et al., 2003). The women in the current study received a reminder from the mammography center 24 hours prior to their appointment, which also may have aided adherence. Further differentiation could have taken place if the adherence data collection occurred longitudinally with logistic regression analysis at the separate intervals of 1, 2, and 3 months instead of cross-sectionally at just the 2-month data collection point. Addition interactions would also be detected.

The U.S. Preventive Services Task Force (2002) recommends screening mammography with or without clinical breast exam every 1-2 years for women aged 40 and older, although screening for women aged 40-49 remains controversial. The Task Force has also found that in randomized trials, the specificity of a single mammographic examination is 94-97%. Adoption, or adherence, to screening can be seen as a continuum in which screeners have the most positive and nonparticipants the most negative breast cancer screening attitudes, beliefs, and early detection behaviors (Mah & Bryant, 1997). The only additional health promotion behavior that was examined in this study was smoking, which was only available in the Phase One analysis. A larger sample size and data on other health promotion behaviors (such as diet and activity) could have better investigated this relationship.

The 12-month versus 24-month interval for mammography screening may reduce the adverse impact of faster growing tumors on mammography sensitivity in younger women (Buist,

Porter, Lehman, Taplin, & White, 2004) The 12-month period selected for this study was appropriate, as evidenced by the recommendation of annual screening in women by the U.S. Preventive Services Task Force.

5.2.4 Self-Selection Bias

In Sweden, taking into account potential biases, changes in clinical practice, and changes in the incidence of breast cancer, mammography screening has been shown to contribute to substantial reductions in breast cancer mortality in two counties (Tabar et al., 2003). Future studies of health maintenance practices in the U.S. need to account for self selection biases in the MS population. The biases could have been a possible contributing factor in this study as evidenced by the high number of women who adhered to mammography screening in Phase Two. However, 86 of 108 did not adhere in Phase One. Self selection biases in cancer screening case-control studies have also been evident (Cronin, Weed, Conner & Prokok, 1998). Random sampling could assist in mitigating this selection bias in studies of women with MS.

An additional bias may have been the relationship the women had with the NMSS. Counseling and confidence in what the NMSS promotes may have influenced the women to get a mammogram when they otherwise would not have. Lay health advisors have influenced the women they counseled because the women knew their advisors well, felt comfortable talking to the advisors about private issues, considered them to be credible sources, and also offered women support with respect to their mammography behavior (Flax & Earp, 1999).

5.3 CONCLUSION

The instruments chosen for the research were tolerated well, useful, administered quickly, and allowed for immediate assessment based upon the results. Despite these aspects of feasibility, it appears that a complex relationship exists between EHBM variables and mammography screening adherence, as evidenced by the conflicting findings in several studies cited.

Mammography is the primary method used for breast cancer screening, yet in the sample of women with MS, adherence remains well below recommended levels. Women who did not adhere tended not to participate in the health care system (as evidenced by the Phase One data), perceived themselves less susceptible to breast cancer, and valued mammography less (as evidenced by Phase Two data).

It is also evident that physician referral was not important in this study. Systematic differences may have occurred in recall of exactly when the physician referral was made, compromising the accuracy of these data.

Although research continues to result in improved methods for detection, at the present time, high quality mammography coupled with adequate breast exams, remain the most effective means of early detection in any population.

To summarize, the Beck Depression Inventory, 2nd edition, the Benefits and Barriers Mammography Screening Scale, the Breast Cancer Knowledge Scale, and the Mammography Screening Self-Efficacy Scale can be used successfully in women who are homebound with MS as part of a phone interview. The sample (N=11) adhered to mammography screening; however. this sample is very small compared to the 149 women screened initially for the NMSS intervention program. Even though this sample in Phase Two was readily accessible, and barriers

were removed, there still was not complete adherence to mammography screening despite subjects perceiving high levels of susceptibility, severity, benefits, and being well educated.

5.3.1 Limitations

The NMSS was unable to enroll 250 women for their intervention program as they had desired. This may have been due to the fact that the project was not a research study, but rather a programmatic clinical intervention study. A research study would have had a more precise research plan, as well as a well documented procedure. Additionally, the midwife was the gatekeeper who initially saw the patients. Since funding limited the program to only one nurse midwife, and she was available only one day a week, this may have contributed to the fact that only half of the predicted sample size was obtained. With doctor's appointments, physical therapy, and other medical modalities, it was difficult, at times, to match the midwife's schedule with that of the subject. Clearly, the sample size was difficult to achieve even after three years of the project implementation. This, in turn, limited the sample size for the dissertation study. The NMSS acted as the initial contact to each subject for the dissertation study.

Analysis was also a limitation due to the small sample size, since only main effects could be examined. In addition, analysis of the modifying variables could not be completed, and the interaction among potential predictors could not be explored.

There were additional limitations of the dissertation study. The short time period for the assessment of mammography adherence (2 months) could have limited subject selection. If the period of time were longer, for example 6 months, greater subject recruitment could have taken place by capturing those who had to postpone their mammogram for another unforeseen event. Additionally, past mammography behavior and current attitudes were assessed by self-report

during the telephone interview, which may have resulted in subjects answering what they perceived the investigator may have wanted to hear, as found by Rutledge et al. (2001).

The short duration of this study may have limited the information obtained and resulted in missed opportunities for further data collection and analysis. The sample was homogenous with respect to sex and the disease process of MS, also limiting generalizability. Additionally, medication information was not obtained, which could have played a role in some of the data collected. The use of antidepressants in this population could have contributed to the low levels of depressive symptomatology and mental status changes reported in the sample.

5.3.2 Recommendations

Recommendations for further study begin with measures. Conceptual framework, sample, and design are also analyzed.

5.3.3 Measures

The validity and reliability of instruments should be assessed in every population studied, yet such analyses were not performed in this study due to small sample size. However, future studies should be planned to permit examination of measurement psychometrics in the population of women with MS. In addition, family caregivers need to be incorporated in measurement of EHBM variables in future studies since they may contribute positively or negatively to health screening adherence by aiding or preventing its conduct. For example, family caregivers may provide cues to action influence the woman by facilitating transportation or encouraging the mammography screening adherence behavior.

The measures used in this study were well tolerated, even though the interview took place over the phone. Implications are that all of the instruments used for this study could be used again to effectively measure variables of the EHBM.

Involvement by the family caregivers in data collection could validate the accurate responses of subjects. With the added benefit of time, not only can the focus be placed on the woman, but the caregiver's perception can be measured as well.

5.3.4 Conceptual Framework

The limited results from this study suggest that the EHBM is appropriate to guide research concerning mammography screening adherence in women with MS. Educational interventions guided by the EHBM can be designed specifically to influence variables related to adherence with early breast cancer detection behaviors. Other interventions that may be tested in this population to improve adherence to mammography screening recommendations could include use of a pool of nurse midwives, or even a full-time nurse midwife, for the home visits.

Reminders have been shown to increase adherence. For example, a telephone call 24 hours prior to the procedure, could be a cue to action evaluated explicitly in future research. Cost needs to be examined in future research studies, for example, by collecting data on co-payments and how often the procedure can be done and still covered by insurance. Effective and targeted counseling for breast cancer screening needs to incorporate elements of provider influence, past mammography behavior, perceptions of mammography screening, and future intention for screening. In addition, adverse effects of mammography need to be studied, such as anxiety, discomfort, and cost associated with positive test results, (many of which are false positive), and the diagnostic procedures they generate.

5.3.4.1 Sample

Women with physical disabilities are at a higher risk for delayed diagnosis of breast cancer. Future research should focus on subpopulations, such as women with disabilities who have low levels of education or income are a member of a minority to rule out an interaction that may have taken place with other modifying factors. Qualitative studies are also needed to determine the meaning of breast cancer screening for women with MS.

Recommendations to increase recruitment include obtaining a sample from a funded research study. In addition, friend referral could enhance the sample numbers in that each subject could be asked to refer someone for the study. It has been found that those with the disease tend to associate with one another. This could be incorporated into the sampling procedure after clearance is obtained by the IRB.

5.3.4.2 Design

Future studies should use random sampling to prevent self-selection of patients. There is a need to evaluate the effect of the screening program on the mortality of breast cancer. Design strategies need to consider past behavior regarding mammography screening as well as current recommendations. The strategies must also incorporate a discussion of beliefs about health preventative behaviors using variables of the EHBM, as well as reinforcement of regular screening behavior.

It is also recommended that future studies lengthen the time intervals for data collection, and to also have collect data at more than one period of time. Data collection monthly for 6 months would capture a more accurate picture of the sample. In addition, a comparison group at the same time intervals would further strengthen the study design.

Trials of mammography screening provide conclusive evidence that the policy of offering screening is associated with a significant and substantial reduction in breast cancer mortality. However, every woman has the right to make an informed decision about her need for mammography screening. Educational resources that promote informed decision making by all women need to be developed. These resources will empower consumers regarding access to cancer screening.

APPENDIX A

DIAGNOSTIC CRITERIA FOR MS (MATTHEWS, 1991)

1. Examination must reveal objective abnormalities of the CNS.
2. Involvement must reflect predominantly disease of white matter long tracts, usually including (a) pyramidal pathways, (b) cerebellar pathways, (c) medial longitudinal fasciculus, (d) optic nerve, and (e) posterior columns
3. Examination or history must implicate involvement of two or more areas of the CNS.
    a. Magnetic resonance imagery (MRI) may be used to document a second lesion when only one site of abnormality has been demonstrable on examination. A confirmatory MRI must have either four lesions involving the white matter or three lesions if one is periventricular in location. Confirmed lesions must be greater than 3 mm in diameter. For patients older than 50 years, two of the following criteria must also be met: (a) lesion size >3mm; (b) lesions about the bodies of the lateral ventricles, and (c) lesion(s) present in the posterior fossa.
    b. Evoked response testing may be used to document a second lesion not evident on clinical examination.

4. The clinical pattern must consist of (a) two or more separate episodes of worsening involving different sites of the central nervous system (CNS), each lasting at least 24 hours and occurring at least 1 month apart, or (b) gradual or stepwise progression over at least 6 months if accompanied by increased cerebral spinal fluid (CSF) IgG synthesis or two or more oligoclonal bands.
5. Age of onset between 15 and 60 years.
6. The patient's neurologic condition could not better be attributed to another disease. Laboratory testing that may be advisable in certain cases includes (a) CSF analysis, (b) MRI of the head or spine, (c) serum B^{12} level, (d) human T cell lymphotropic virus type I (HTLV-I) titer, (e) erythrocyte sedimentation rate, (f) rheumatoid factor, antinuclear, anti-DNA antibodies (SLE), (g) serum VDRL, (h) angiotensin-converting enzyme (sarcoidosis), (I) Borrelia serology (Lyme disease), (j) very long chain fatty acids (adrenoleukodystrophy), and (k) serum or CSF lactate, muscle biopsy, or mitochondrial DNA analysis (mitrochondrial disorders).

DIAGNOSTIC CATEGORIES

1. *Definite MS:* All six criteria fulfilled.
2. *Probable MS:* All six criteria fulfilled except (a) only one objective abnormality despite two symptomatic episodes or (b) only one symptomatic episode despite two or more objective abnormalities.
3. *At risk for MS:* All six criteria fulfilled except only one symptomatic episode and one objective abnormality.

APPENDIX B

INITIAL SYMPTOMS OF MS (MATTHEWS, 1991)

SYMPTOMS	PERCENT OF CASES
Sensory loss	37
Optic neuritis	36
Weakness	35
Paresthesias	24
Diplopia	15
Ataxia	11
Vertigo	6
Paroxysmal attacks	4
Bladder	4
Lhermitte	3
Pain	3
Dementia	2
Visual loss	2
Facial palsy	1
Impotence	1
Myokemia	1
Epilepsy	1
Falling	1

APPENDIX C

BREAST CANCER SCREENING RECOMMENDATION

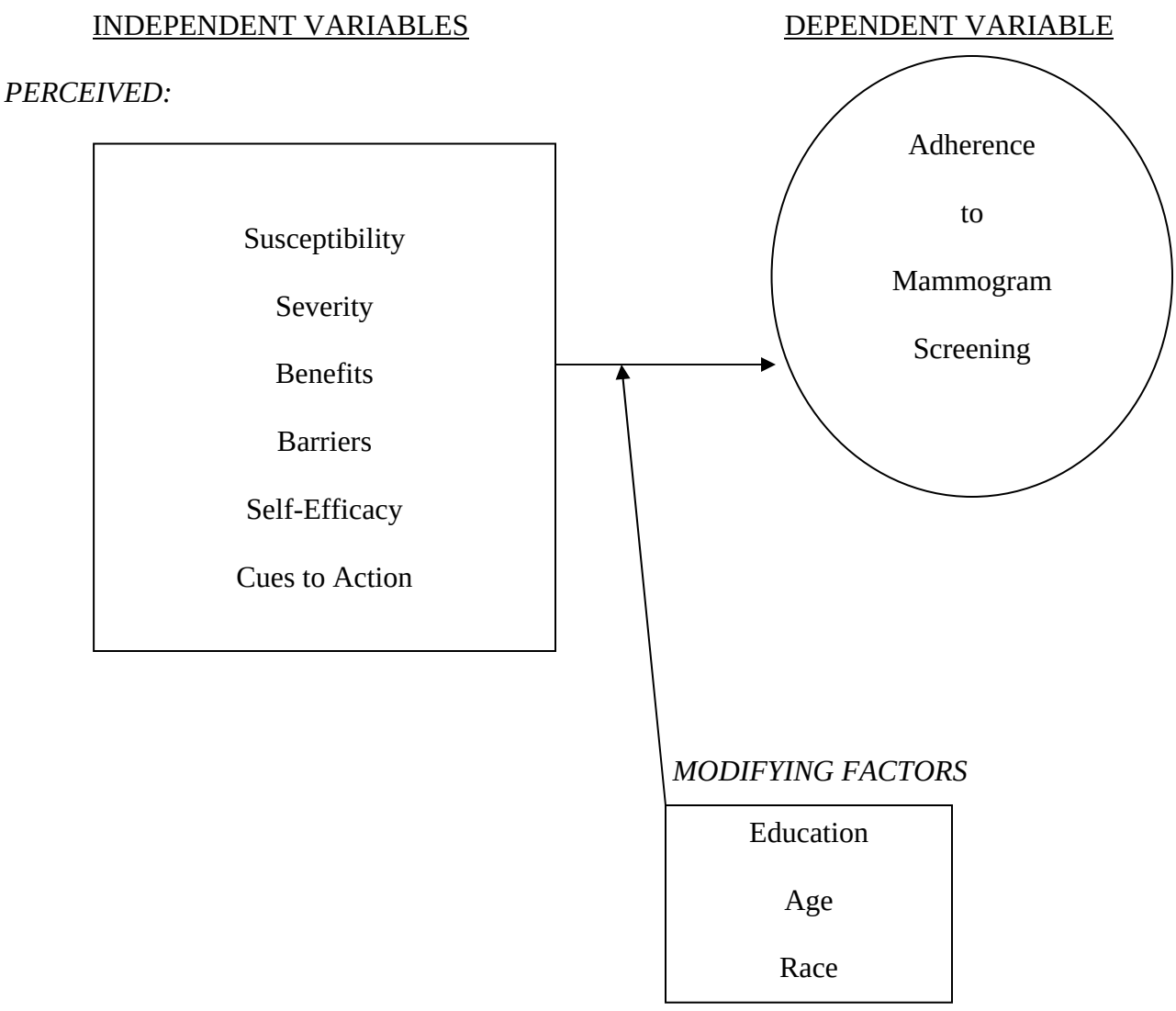
(U.S. PREVENTIVE TASK FORCE, 2002)

Women who are at increased risk for breast cancer (e.g., Those with a family history of breast cancer in a mother or sister, a previous breast biopsy revealing atypical hyperplasia, or first childbirth after age 30) are more likely to benefit from regular mammography than women at lower risk. The recommendation for women to begin routine screening in their 40s is strengthened by a family history of breast cancer having been diagnosed before menopause.

In the trials that demonstrated the effectiveness of mammography in lowering breast cancer mortality, screening was performed every 12-33 months. For women aged 50 and older, there is little evidence to suggest that annual mammography is more effective than mammography done every year. For women aged 40-49, available trials also have not reported a clear advantage of annual mammography over biennial mammography. Nevertheless, some experts recommend annual mammography based on the lower sensitivity of the test and on evidence that tumors grow more rapidly in this age group.

APPENDIX D

CONCEPTUAL MODEL (PROPOSED)



APPENDIX E

KURTZKE EXPANDED DISABILITY STATUS SCALE (EDSS) (KURTZKE, 1983)

0.0=Normal neurologic exam [all grade 0 in functional status (FS)]

1.0=No disability, minimal signs in one FS (i.e. grade 1)

1.5=No disability, minimal signs in more than one FS (more than one grade 1)

2.0=Minimal disability in one FS (one FS grade 2, others 0 or 1)

2.5=Minimal disability in two FS (two FS grade 2, other 0 or 1)

3.0=Moderate disability in one FS (one FS grade 3, others 0 or 1) or mild disability in three or four FS (three/four FS grade 2, others 0 or 1) though fully ambulatory

3.5=Fully ambulatory but with moderate disability in one FS (one grade 3) and one or two FS grade 2; or two FS grade 3; or five FS grade 2 (others 0 or 1)

4.0=Ambulatory without aid or rest for > 500 m

4.5=Ambulatory without aid or rest for >300 m

5.0=Ambulatory without aid or rest for >200m

5.5=Ambulatory without aid or rest for >100m

6.0=Unilateral assistance required to walk about 100 m with or without resting

6.5=Constant bilateral assistance required to walk about 20 m without resting

7.0=Unable to walk beyond about 5 m even with aid; essentially restricted to wheelchair; wheels self and transfers alone

7.5=Unable to take more than a few steps; restricted to wheelchair; may need aid to transfer

8.0=Essentially restricted to bed or chair or perambulated in wheelchair, but out of bed most of the day; retains many self-care functions; generally has effective use of arms

8.5=Essentially restricted to bed much of the day; has some effective use of arm(s); retains some self-care functions

9.0=Helpless bed patient; can communicate and eat

9.5=Totally helpless bed patient; unable to communicate or eat

10.0=Death due to MS

FUNCTIONAL STATUS (FS) SCORE

A. Pyramidal functions

0=Normal

1=Abnormal signs without disability

2=Minimal disability

3=Mild or moderate paraparesis or hemiparesis, or severe monoparesis

4=Marked paraparesis or hemiparesis, moderate quadriparesis, or monoplegia

5=Paraplegia, hemiplegia, or marked quadriparesis

6=Quadriplegia

B. Cerebellar function

0=Normal

1=Abnormal signs without disability

2=Mild ataxia

3=Moderate truncal or limb ataxia

4=Severe ataxia all limbs

5=Unable to perform coordinated movements due to ataxia

C. Brainstem functions

0=Normal

1=Signs only

2=Moderate nystagmus or other mild disability

3=Severe nystagmus, marked extraocular weakness, or moderate disability of other cranial nerves

4=Marked dysarthria or other marked disability

5=Inability to swallow or speak

D. Sensory functions

0=Normal

1=Vibration or figure-writing decrease only, in 1 or 2 limbs

2=Mild decrease in touch or pain or position sense, and/or moderate decrease in vibration in 1 or 2 limbs, or vibratory (c/s figure writing) decrease alone in 3 or 4 limbs

3=Moderate decrease in touch or pain or position sense, and/or essentially lost vibration in 1 or 2 limbs, or mild decrease in touch or pain, and/or moderate decrease in all proprioceptive tests in 3 or 4 limbs

4=Marked decrease in touch or pain or loss of proprioception, alone or combined, in 1 or 2 limbs or moderate decrease in touch or pain and/or severe proprioceptive decrease in more than 2 limbs

5=Loss (essentially) of sensation in 1 or 2 limbs or moderate decrease in touch or pain and/or loss of proprioception for most of the body below the head

6=Sensation essentially lost below the head

E. Bowel and bladder functions

0=Normal

1=Mild urinary hesitancy, urgency, or retention

2=Moderate hesitancy, urgency, retention of bowel or bladder, or rare urinary incontinence

3=Frequent urinary incontinence

4=In need of almost constant catheterization

5=Loss of bladder function

6=Loss of bowel and bladder function

F. Visual (or optic) function

0=Normal

1=Scotoma with visual acuity (corrected) better than 20/30

2=Worse eye with scotoma with maximal visual acuity (corrected) of 20/30 to 20/59.

3=Worse eye with large scotoma, or moderate decrease in fields, but with maximal visual acuity (corrected) of 20/60 to 20/99

4=Worse eye with marked decrease of fields and maximal acuity (corrected) of 20/100 to 20/200; grade 3 plus maximal acuity of better eye of 20/60 or less

5=Worse eye with maximal visual acuity (corrected) less than 20/200; grade 4 plus maximal acuity of better eye of 20/60 or less

6=Grade 5 plus maximal visual acuity of better eye of 20/60 or less

G. Cerebral (or mental) functions

0=Normal

1=Mood alteration only (does not affect EDSS score)

2=Mild decrease in mentation

3=Moderate decrease in mentation

4=Marked decrease in mentation

5=Chronic brain syndrome-severe or incompetent

APPENDIX F

BECK DEPRESSION INVENTORY II

Name: _____

ID: _____

This questionnaire consists of 21 groups of statements. I will read each group of statements to you carefully, and then want you to pick out the one statement in each group that best describes the way you have been feeling during the past two weeks, including today.

1. Sadness

0 I do not feel sad.
1 I feel sad much of the time.
2 I am sad all the time.
3 I am so sad or unhappy that I can't stand it.

2. Pessimism

0 I am not discouraged about my future.
1 I feel more discouraged about my future than I used to be.
2 I do not expect things to work out for me.
3 I feel my future is hopeless and will only get worse.

3. Past Failure

0 I do not feel like a failure.
1 I have failed more than I should have.
2 As I look back, I see a lot of failures.
3 I feel I am a total failure as a person.

4. Loss of Pleasure

0 I get as much pleasure as I ever did from the things I enjoy.
1 I don't enjoy things as much as I used to.
2 I get very little pleasure from the things I used to enjoy.

3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

0 I don't feel particularly guilty.
1 I feel guilty over many things I have done or should have done.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.

6. Punishment Feelings

0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

7. Self-Dislike

0 I feel the same about myself as ever.
1 I have lost confidence in myself.
2 I am disappointed in myself.
3 I dislike myself.

8. Self-Criticalness

0 I don't criticize or blame myself more than usual.
1 I am more critical of myself than I used to be.
2 I criticize myself for all of my faults.
3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would no carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

10. **Crying**

0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would no carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

11. Agitation

0 I am no more restless or wound up than usual.
1 I feel more restless or wound up than usual.
2 I am so restless or agitated that it's hard to stay still.
3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0 I have not lost interest in other people or activities.
1 I am less interested in other people or things than before.
2 I have lost most of my interest in other people or things.
3 It's hard to get interested in anything.

13. Indecisiveness

0 I make decisions about as well as ever.
1 I find it more difficult to make decisions than usual.
2 I have much greater difficulty in making decisions than I used to.
3 I have trouble making any decisions.

14. **Worthlessness**

0 I do not feel I am worthless.
1 I don't consider myself as worthwhile and useful as I used to.
2 I feel more worthless as compared to other people.
3 I feel utterly worthless.

15. **Loss of Energy**

0 I have as much energy as ever.
1 I have less energy than I used to have.
2 I don't have enough energy to do very much.
3 I don't have enough energy to do anything.

16. **Changes in Sleeping Pattern**

0 I have not experience any change in my sleeping pattern.
1a I sleep somewhat more than usual
1b I sleep somewhat less than usual.
2a I sleep a lot more than usual.
2b I sleep a lot less than usual.
3a I sleep most of the day.
3b I wake up 1-2 hours early and can't get back to sleep.

17. Irritability

0 I am no more irritable than usual.
1 I am more irritable than usual.
2 I am more irritable than usual.
3 I am irritable all the time.

18. **Changes in Appetite**

0 I have not experienced any change in my appetite.
1a My appetite is somewhat less than usual.
1b My appetite is somewhat greater than usual.
2a My appetite is much less than before.
3a I have no appetite at all.
3b I crave food all the time.

19. Concentration Difficulty

0 I can concentrate as well as ever.
1 I can't concentrate as well as usual.
2 It's hard to keep my mind on anything for very long.
3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

0 I am no more tired or fatigued than usual.
1 I get more tired or fatigued more easily than usual.
2 I am too tired or fatigued to do a lot of the things I used to do.
3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0 I have not noticed any recent change in my interest in sex
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

APPENDIX G

SF-36

Mammography Screening Behaviors in Relation to the Expanded Health Belief Model in a Sample of Homebound Women with Multiple Sclerosis

DATE: _____

ID: _____

This survey asks for your views about your health. This information will help us determine how you feel and how well you are able to do usual activities. Answer each question by selecting the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

   Excellent Very good Good Fair Poor

2. *Compared to one year ago*, how would you rate your health in general *now*?

   Much better now Somewhat better now About the same

   Somewhat worse now Much worse now

3. The following questions are about activities you might do during a typical day. Does your health *now* limit you in these activities? If so, how much?

   Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports:

   Yes, limited a lot Yes, limited a little No, not limited at all

Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:

Yes, limited a lot Yes, limited a little No, not limited at all

Lifting or carrying groceries:

Yes, limited a lot Yes, limited a little No, not limited at all

Climbing **several** flights of stairs

Yes, limited a lot Yes, limited a little No, not limited at all

Climbing **one** flight of stairs

Yes, limited a lot Yes, limited a little No, not limited at all

Bending, kneeling, or stooping

Yes, limited a lot Yes, limited a little No, not limited at all

Walking **more than a mile**

Yes, limited a lot Yes, limited a little No, not limited at all

Walking **several blocks**

Yes, limited a lot Yes, limited a little No, not limited at all

Walking **one block**

Yes, limited a lot Yes, limited a little No, not limited at all

Bathing or dressing yourself

Yes, limited a lot Yes, limited a little No, not limited at all

4. During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

Cut down on the **amount of time** you spent on work or other activities

Yes No

Accomplished less than you would like

Yes No

Were limited in the **kind** of work or other activities

Yes No

Had **difficulty** performing the work or other activities (for example, it took extra effort)

Yes No

5. During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities *as a result of any emotional problems* (such as feeling depresses or anxious)?

   Cut down the **amount of time** you spent on work or other activities

   Yes No

   Accomplished less than you would like

   Yes No

   Didn't do work or other activities as **carefully** as usual

   Yes No

6. During the *past 4 weeks,* to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

   Not at all Slightly Moderately Quite a bit Extremely

7. How much *bodily* pain have you had during the *past 4 weeks?*

   None Very mild Mild Moderate Severe Very severe

8. During the *past 4 weeks,* how much did pain interfere with your normal work (including both work outside the home and housework)?

   Not at all A little bit Moderately Quite a bit Extermely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

   How much of the time during the *past 4 weeks*.....

Did you feel full of pep?

All of the time Most of the time A good bit of the time

Some of the time A little of the time None of the time

Have you been a very nervous person?

All of the time Most of the time A good bit of the time

Some of the time A little of the time None of the time

Have you felt so down in the dumps that nothing could cheer you up?

All of the time Most of the time A good bit of the time

Some of the time A little of the time None of the time

Have you felt calm and peaceful?

All of the time Most of the time A good bit of the time

Some of the time A little of the time None of the time

Did you have a lot of energy?

All of the time Most of the time A good bit of the time

Some of the time A little of the time None of the time

Have you felt downhearted and blue?

All of the time Most of the time A good bit of the time

Some of the time A little of the time None of the time

Did you feel worn out?

All of the time Most of the time A good bit of the time

Some of the time A little of the time None of the time

Have you been a happy person?

All of the time Most of the time A good bit of the time

Some of the time A little of the time None of the time

Did you feel tired?

All of the time Most of the time A good bit of the time

Some of the time A little of the time None of the time

10. During the *past 4 weeks*, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time Most of the time Some of the time A little of the time

None of the time

11. How TRUE or FALSE is *each* of the following statements for you?

I seem to get sick a little easier than other people

Definitely true Mostly true Don't know Mostly false Definitely false

I am as healthy as anybody I know

Definitely true Mostly true Don't know Mostly false Definitely false

I expect my health to get worse

Definitely true Mostly true Don't know Mostly false Definitely false

My health is excellent

Definitely true Mostly true Don't know Mostly false Definitely false

APPENDIX H

MINI-MENTAL STATES EXAMINATION

ORIENTATION TO TIME

What is the year?
What is the season?
What is the month of the year?
What is the day of the week?
What is the date?

ORIENTATION TO PLACE

Where are you now?
What is the state?
What is the county?
What is the city?
What is the address?

Scoring: 1 for each accurate response, 0 if inaccurate

APPENDIX I

BENEFITS AND BARRIERS MAMMOGRAPHY SCREENING TEST

Mammography Screening Behaviors in Relation to the Expanded Health Belief Model in a Sample of Homebound Women with Multiple Sclerosis

DATE:_____

ID: _____

1. When I get a recommended mammogram, I feel good about myself.

   Strongly disagree Disagree Neutral Agree Strongly agree

2. When I get a mammogram, I don't worry as much about cancer.

   Strongly disagree Disagree Neutral Agree Strongly agree

3. My doctor or nurse will praise me if I obtain the recommended mammogram.

Strongly disagree Disagree Neutral Agree Strongly agree

4. Having a mammogram or x-ray of the breasts will help me find lumps early.

Strongly disagree Disagree Neutral Agree Strongly agree

5. Having a mammogram or x-ray of the breasts will decrease my chances of dying from breast cancer.

Strongly disagree Disagree Neutral Agree Strongly agree

6. Having mammogram or x-ray of the breasts will decrease my chances of requiring radical or disfiguring surgery if breast cancer occurs

Strongly disagree Disagree Neutral Agree Strongly agree

7. Having a mammogram will help find a lump before it can be felt by myself or a health professional

Strongly disagree Disagree Neutral Agree Strongly agree

8. Having a routine mammogram or x-ray of the breasts would make me worry about breast cancer

Strongly disagree Disagree Neutral Agree Strongly agree

9. Having a mammogram or x-ray of the breasts would be embarrassing

Strongly disagree Disagree Neutral Agree Strongly agree

10. Having a mammogram or x-ray of the breasts would take too much time

Strongly disagree Disagree Neutral Agree Strongly agree

11. Having a mammogram or x-ray of the breasts would be painful

Strongly disagree Disagree Neutral Agree Strongly agree

12. Having a mammogram or x-ray of the breasts would cost too much money

Strongly disagree Disagree Neutral Agree Strongly agree

APPENDIX J

BREAST CANCER KNOWLEDGE TEST

Mammography Screening Behaviors in Relation to the Expanded Health Belief Model in a Sample of Homebound Women with Multiple Sclerosis

DATE: _____

ID: _____

Please answer the following questions as either true or false:

GENERAL KNOWLEDGE

1. A hard blow to the breast may cause a woman to get breast cancer later in life.

   True False

2. The constant irritation of a tight bra can, over time, cause breast cancer.

   True False

3. One out of every 10 women in the United States will get breast cancer sometime during her life.

   True False

4. In some women, being overweight increases the risk of developing breast cancer.

   True False

5. A woman who bears her first child before the age of 30 is more likely to develop breast cancer than a woman who bears her first child after the age of 30.

   True False

6. Women with no known risk factors for breast cancer rarely get breast cancer.

   True False

7. Some types of fibrocystic breast disease (noncancerous breast lumps) increase a woman's risk of breast cancer.

   True False

8. Women in the United States have a higher risk of breast cancer than do women in Asia or Africa.

   True False

9. Breast cancer is more common in 65-year-old women than in 40-year-old women.

   True False

10. The most frequent occurring in women is breast cancer.

    True False

11. Women over age 70 rarely get breast cancer.

    True False

12. Most breast lumps are cancerous.

True False

CURABILITY

1. For many women, breast cancer can now be successfully treated without breast removal (mastectomy).

   True False

2. By the time a cancerous breast lump is painful, it is too late to be successfully treated.

   True False

3. If all lymph glands around the breast and under the arm are not removed, breast cancer cannot be cured.

   True False

4. Breast cancer is sometimes treated successfully by removal of the lump (lumpectomy) and radiation therapy.

   True False

5. Breast cancer is less likely to be cured in women with a family history of breast cancer than in women with no family history of breast cancer.

   True False

6. By the time a woman can feel a cancerous breast lump, it is too late to treat it effectively.

   True False

7. Even if breast cancer is caught very early, the chances for cure are much better if the whole breast is removed.

   True False

8. Even if detected and treated early, a woman with breast cancer is unlikely to live a normal life span.

True False

APPENDIX K

MAMMOGRAPHY SCREENING SELF-EFFICACY SCALE

Name: _____

ID: _____

These are questions about how likely it would be for you to have a mammogram this year, given a variety of situations. A mammogram is a medical test to see if a woman has breast cancer. The answers are on a 0 to 10 scale, with 0 indicating not at all likely, and 10 representing very likely.
HOW LIKELY IS IT THAT YOU WOULD HAVE A MAMMOGRAM THIS YEAR IF….

1. You were mailed a postcard asking you to call for an appointment?

2. You were called by your doctor's office to schedule your annual mammogram?

3. You received no reminder?

4. The nurse from the clinic or doctor's office were to say that you should have one?

5. You were told by your doctor that it was time to have a mammogram?

6. An important family member or friend were to urge you to have one?

7. Someone else were to make the appointment for you?

8. You were to go alone to your appointment?

9. Someone were to go with you for your appointment?

10. A friend or relative were to go with you and have hers at the same time?

11. You figured there wasn't much chance you would ever get breast cancer?

12. You had a friend or acquaintance with breast cancer?

13. You had a mother or sister with breast cancer?

14. You suspected you had symptoms of breast cancer, like a lump, thickening, or nipple discharge?

15. You had no symptoms?

16. You wouldn't have to wait more than 10 minutes for your mammogram?

17. You would drop in without an appointment?

18. You might have to wait 30 minutes or more for a mammogram?

19. You were told there was very little radiation with a mammogram?

20. You could have your mammogram on the same day as a regularly scheduled medical appointment?

21. You had to make a separate visit for the mammogram?

22. You had to pay the full cost of the mammogram yourself?

23. You had to pay half the cost yourself?

24. You didn't have to pay any of the cost?

25. You were told the results before you left the place where the mammogram was done?

26. You had to wait 1 or 2 weeks before getting the results?

27. It were easy to get where the mammogram was to be done, in terms of location, parking, or public transportation?

28. A ride were provided for a small fee?

29. Transportation were free?

30. You needed to drive or be driven and had to pay to park?

31. You thought a mammogram would be uncomfortable or painful?

32. You were to see a billboard urging women to have a mammogram?

33. You were to read a newspaper or magazine article urgin women your age to have one?

34. You were to see an ad on TV about breast cancer screening?

35. You were to watch a TV show about breast cancer?

36. Your visiting nurse were to tell you it was time to get one?

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